

**EXISTENTIAL LOSS IN THE CONTEXT OF MOTOR
NEURONE DISEASE: A HERMENEUTIC
PHENOMENOLOGICAL STUDY**

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Submitted in Fulfilment of the Requirements of the
Master of Philosophy, September, 2014**

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GLOSSARY OF TERMS

Being-in-the-world	Heidegger describes our inevitable involvement with all that is: this involvement he terms ‘care’. We do not enter the world from the outside but we are always part of it. This inseparable relation is implied by the three hyphens (Cohn, 1997, p.13).
Being-in-the-world-with-others	Relatedness is a primary state of being – we cannot choose a world without other people. However, we can choose how to respond to this primary relatedness – what is also termed ‘intersubjectivity’ – we can concern ourselves with it or turn our back on it. Over-involvement and isolation are both responses to being-with-others (Cohn, 1997, p.13).
Dasein	Heidegger refers to the human being and to the type of being that humans have as Dasein. Dasein means to exist or to be there, or be here (Inwood, 1997, p22).
Embodiment	All being is physical and non-physical (Cohn, 1997). The non-physical being relates to psychological, social and spiritual dimensions (van Deurzen and Baker, 2005). Heidegger focused on embodiment as ways of being (physical, psychological, social and spiritual) (Inwood, 1997).
Existential	Pertaining to the experience of existence (Oxford English Dictionary, 1984).
Hermeneutics	The art of interpretation or understanding (Moran, 2000, p.248).
Illness trajectory	The course of an illness over time, plus the actions of clients, families and health care professionals to manage that course (Corbin and Strauss, 1991).
Interpretation	Heidegger claims that we do not first perceive something purely present at hand and then interpret it as, for example, a house; rather we encounter things as already interpreted in terms of a web of possibilities which we apprehend the thing as possessing. In every case, interpreting is grounded in something we have in advance – in fore-having (Moran, 2000, p.271).
Lifeworld	Heidegger (1927/1962) outlines the key structures of existence (also called Lifeworld). He argues that we all have an embodied sense of self, which is always in relation to others, while our consciousness is shared with others through language, discourse, culture and our history (Finlay, 2011, p.18). The lifeworld, with all that is significant for us, is fundamental to us (Polt, 1999).
Melancholia	In a modern context, ‘melancholy’ applies only to the mental or emotional symptoms of depression or despondency; historically ‘melancholia’ could be physical as well as mental, and melancholic conditions were classified as such by their common cause rather than by their properties (Berrios, 1988).

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Mood	Describes the affective aspect of experience of being-in-the-world. Mood does not respond to what it meets, it also discloses it. For example, anxiety is not just a response to being thrown into the world; it is only through anxiety that a person becomes aware of this thrownness (Cohn, 1997, p.13).
Mortality	The awareness of the inevitability of death is a prerogative of human beings. It is our ultimate limitation, which we can deny or accept as an intrinsic aspect of the process of living (Cohn 1997, p.13).
Spatiality	If existence is 'being-in-the-world', it is 'spatial' – that is, part of a wider context to which it is related. But the space between different parts of this context is not measurable in feet and yards but is experienced differently at different times; what is close today, can be distant tomorrow (Cohn, 1997, p.13).
Spirituality	An individual's sense of peace, purpose and connection to others, and beliefs about the meaning of life (NCI, 2008).
Temporality	Similarly we are 'temporal', as we are our history, moving from birth to death. But this movement is not experienced as a linear one-after-the-other, as the hand of a clock moves from one moment to the next, but the past is carried along by a present that is already anticipating the future (Cohn, 1997, p.13).
Thrownness	This indicates the limits of our control over existence. Our life is conditioned in many ways; from birth onwards we find ourselves in unchosen situations, or 'thrown'. These situations include what Heidegger calls 'facticity' – our past history which in itself cannot be changed, though our response to it can (Cohn, 1997, p.13).
Understanding	A fundamental structure of Dasein: all understanding involves self-understanding (Moran, 2000, p.277).

DEDICATION

This thesis is dedicated to my mother, who lived through her illness trajectory of MND with such courage and grace. It is also dedicated to the participants taking part in my study and all other people diagnosed and living with MND, as well as those who care for them.

ACKNOWLEDGEMENTS

I wish to express immense gratitude to the four people who gave their time and energy to share their story.

I am extremely grateful to Dr Jackie Taylor, Mr Michael Ravey and Dr Julie Nightingale for their support, guidance and supervision.

I wish to acknowledge the support of Dr John Ealing and the nurses Rosemary Morris and Samantha Holden at the MNDA Centre for helping to recruit the participants to the study.

I would also like to acknowledge the early guidance of Tom Wengraf, Bridget Taylor and Sinead O'Toole, and latterly the guidance of Linda Finlay.

I am grateful to Debbie Whittaker whose early support for this project was extremely encouraging.

I thank Ms Mhorag Goff, Ms Sheryl Buckley and Ms Gemma Duffy for their support and encouragement which has sustained me through this project.

I wish to acknowledge the support and help that I received from my colleagues in the School of Occupational Therapy, especially those who understood the challenges I faced completing a thesis in three years, whilst also fulfilling my teaching commitments.

I am grateful to the MNDA for accepting my work for the 24th International Symposium on ALS/MND, Milan, Italy, 6-8 December 2013.

Most importantly I wish to thank my family: husband Danny, children Nicol, Christopher and Bethany, because without their continued support, tolerance and love, I would not have got through the last four years.

Finally, I am so grateful to my granddaughter Ava-Mae, for her unconditional love.

ABSTRACT

Motor Neurone Disease (MND) is a rare, devastating neurodegenerative disease of middle/late life, usually presenting in the sixth and seventh decades (McDermot and Shaw, 2008). People have to wait many months to receive their diagnosis of MND (Donaghy, Dick, Hardiman and Patterson, 2008), and they have already experienced the degenerative nature that characterises MND (Bolmsjö, 2001). However, information on the meaning of life with MND through time is limited. The aim was to answer the research question: “What does it mean to be a person living through the illness trajectory of MND?” and to study the phenomenon of existence when given a diagnosis of MND and in the context of receiving health care.

Hermeneutic phenomenology informs the methodological approach which asks the question: “Can you please tell me the story of your life... since you first thought there might be something wrong with you?” Hermeneutic analysis involved a five-stage process in order to understand (interpret) the lifeworld¹ of four people diagnosed with MND. A lifeworld perspective helped to make sense of the meaning of existence when given a terminal diagnosis of MND. The concept of ‘existential loss’ identified in relation to MND was a loss of past ways of being-in-the-world: loss of embodiment, loss of spatiality, and loss of future. The concept of existential loss requires closer attention by health care professionals from the time of diagnosis and through the illness trajectory. The findings are conceptualised into a framework which, used as a clinical tool, may prompt health care professionals to focus on their patient’s existential loss and existential concerns. This study adds to the existing literature that is calling for a lifeworld approach to health care.

¹ Lifeworld – Being-in-the-world (Finlay, 2011; Polt, 1999)

PRELUDE

Being an occupational therapist in the community, I understood in my practice that observing is central to the care process, as is listening to a patient's physical, psychological, social and spiritual concerns. I kept a journal of events and experiences whilst supporting my mother living through her illness trajectory² of progressive bulbar palsy motor neurone disease (PBP MND). I argue that the rapid descent towards an unexpected end-of-life challenges a person's spirituality and meaning of existence. I also argue that, if a person's spirituality and concerns for existence are not explored whilst they still have the capacity to communicate, this can result in existential suffering. The experiences of observing continuing health care being delivered in the home context brought me to this study.

I noticed on Boxing Day 2008 that Mum was slurring her words. It took eight months for her finally to be diagnosed with PBP type MND, after a series of neurological tests and a brain scan. I now understand why it takes so long: MND initially presents itself as so many other neurological conditions. In the first two months, we carried on with life as normal; Mum continued to drive, shop, and to visit her family. She had already lost many of her friends, as she could no longer work as a credit controller for the family business, or go to the weekly Women's Institute (WI) meetings; she was embarrassed by her inability to speak. She continued to communicate with us using a pen and paper, until the speech and language therapist introduced her to the Lightwriter, and this became her lifeline.

At the time of diagnosis my mother was told that her MND was progressing quickly, and that there was no known cure. She was given the medication Riluzole and told that, taken daily, this drug could prolong her life for three months. Compliant, she took the drug daily and on the hour. At the time of diagnosis it was recommended that she should consider having a

² An illness trajectory - the course of an illness over time, plus the actions of clients, families and health care professionals to manage that course (Corbin and Strauss, 1991).

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percutaneous endoscopic gastrostomy (PEG) feed to improve her quality of life when she could no longer take fluids and nutrition. My mother did not ask her consultant how her disease would progress, and she did not want to read the information provided by the MND Association either. I was grateful the consultant had not discussed how the illness trajectory would progress, but only because I wished to keep hope alive in the months that were to follow the diagnosis. I also understood mum was making decisions on whether to have a PEG feed based on limited information. The implications of having the PEG greatly impact on end-of-life care; and whether the continuation of feed should be maintained when she no longer had a quality of life was not discussed. The initial attempt to insert the PEG tube failed and, despite being told that her disease was rapidly progressive, she waited two months to have the procedure done under non-invasive ventilation, by which time, she could no longer take food and drink orally. My mother was admitted into hospital to receive intravenous fluids and nutrition, because this was not available as a procedure that could be carried out at home.

At the time of diagnosis, my mother was told that she would be referred to the community palliative care team. This was the same care team that had been involved in my previous research, where I found that health care providers had limited awareness, knowledge and understanding of the Mental Capacity Act (2005) and its implications for people nearing their end of life (Harris and Fineberg, 2011). I anticipated ethical complications in the care context. The week after being diagnosed my mother had arranged an appointment with her solicitor to put in place a Lasting Power of Attorney (LPA) to designate my brother and me as proxies for all her health care decisions. This was then registered with the Office of the Public Guardian. What this meant was that all health care decisions made when she no longer had capacity to communicate by any means would have to be agreed with either one of us.

During the second stage of her MND, my mother needed help with all the activities of daily living. I visited her four times a day to get her washed and dressed and to prepare meals and provide emotional support. In the beginning my mother was emotionally strong; she had gone through much in her life that gave her the inner strength to survive her experience. I was concerned that my mother needed to express her concerns for life and death, and my need to keep hope alive was impacting on her freedom to have a voice. She did discuss her fears of becoming a burden to the family with a member of the palliative care team. She later told me

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this through the Lightwriter, and we broke down together. On another day she allowed herself to express her upset in front of me, when the notice came from the DVLA stating that she was no longer fit to drive. My mother losing her wheels was like an angel losing her wings, and for her this meant a loss of independence.

The final day came of her life at home alone. At tea time we chatted via the Lightwriter and Mum agreed that it was time to call for the G.P. As we sat waiting for the G.P. to arrive, Mum took off all her jewellery, handed it to me, and typed into her Lightwriter that she would not be needing it anymore: “they’re yours.” I liken the experience to Frankl’s 1959 story of being taken from his home and stripped of all his possessions, before being taken to Auschwitz not knowing his fate; except that my mother was waiting for an ambulance to take her to the local NHS hospital. Like Frankl, my mother believed that she would not be returning to her home.

During the third stage of her MND, my mother was admitted to a ward and into a small, very dingy side room. She remained on a drip, which provided her with fluids and nutrients for three weeks, waiting to be transferred to a specialist hospital for respiratory functioning, where she would receive her PEG using non-invasive ventilation. During this time she lost her ability to mobilise and transfer independently. Her upper limbs were becoming weak and she was becoming less able to use her Lightwriter. Faced with such physical loss, she could still find her sense of humour. This time the PEG procedure was a success. The multidisciplinary team assessed her needs, and felt that she required continuing health care. Despite all the equipment and care being in place at her home, she was returned to the local NHS hospital.

Her readmission was not without event: she contracted a hospital-acquired Norovirus infection, she was now dependent for all her needs, and she was told whilst alone that she was not for resuscitation. The day came for her discharge, with continuing health care, six weeks after her admission for hydration. Despite her experiencing loss of speech, movement, roles, relationships, autonomy and her sense of temporality, my mother was in her preferred place of care: we had brought her home. Not through choice, I became the care coordinator in this context. I understood that it was not my role to monitor and order medication and supplies. This meant that I could not focus on giving the emotional support to my mother and my

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family, as I would wish to do. Other challenges included the lack of provision of much-needed specialist equipment with a head support. I considered how the primary focus of care was meeting my mother's physical needs, in the hope that medication would help her psychological distress. Her spirituality³ and existential⁴ concerns for life and death had not been explored when she was still able to communicate, although as mentioned earlier concerns about becoming a burden were discussed.

In the final stages of her MND, my mother cried continuously for almost two months, which was distressing for all concerned. A hospice consultant conducted a review in the home; the Macmillan nurse stated how unusual it was for this to happen. He took her off one of her medications, Baclofen, because of its noted psychotic effects. At this time I raised my concerns for feed being continuously given via the PEG. In the initial months of receiving feed down the PEG my mother would indicate when she was full, usually by raising her arm when the bag of feed was half way. When she could no longer move, the nurses continued to let the whole of the feed go through. I raised this as an ethical dilemma and requested that the nursing team ask my mother if she was full or not. It was reasoned by the health care professionals that all of the feed should be given to prevent pressure sores.

In the later weeks my brother and I were asked to consider whether my mother should be given a syringe driver. Over the weekend my brother and I determined that our mother still had the capacity to make that decision for herself. We understood when our mother refused because she wished to remain alert, orientated and in control of the end of her life. Just as midwives usher newborns into the world, we were told by one experienced nurse that we must "keep talking, she can still hear you".

The concern for me as a daughter, a carer, a therapist and a researcher, observing other health care professionals struggling to manage the complexity of MND brought me to this study. As a health care professional I hold that most of the health care professionals were proficient in the care they delivered; the care focus was on meeting the medical and practical needs of my

³ Spirituality is defined as an individual's sense of peace, purpose and connection to others, and beliefs about the meaning of life (NCI, 2008).

⁴ Existential – the experience of existence (Oxford English Dictionary).

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mother. The concern was that her spirituality and existential concerns were accorded secondary importance. This came to the forefront when her main carer for 5 months stated after the funeral: "I learnt more about Audrey through her eulogy than I had in all the time I have looked after her". I hold that in order to provide holistic care (physical, psychological, social and spiritual) health care professionals need to see beyond the person with a disease with medical and physical needs, and to understand they are a person with their own unique spirituality who just happens to have MND. I also believe that the person and their family can get lost in the context of health care that focuses on the person with MND and their medical and physical needs. Despite palliative care professionals overseeing the nursing care being delivered in the home context, I had to seek help with counselling for myself and my youngest daughter. I understand that my experience of supporting my mother living with MND is a unique experience, but I come to the literature and this study with a number of unanswered questions:

1. What is the meaning of existence for others when given a diagnosis of MND?
2. What are other people's existential concerns?
3. Do other people get the chance to affirm life and death as a normal process?
4. Do other people get the opportunity to discuss and document their needs, priorities and preferences for their end of life?
5. What is the experienced focus of care for other people diagnosed with MND?

CHAPTER 1 - INTRODUCTION TO THE THESIS AND STUDY

1.1 BACKGROUND

Motor Neurone Disease (MND) is a rare, devastating neurodegenerative disease of later life, usually presenting in the sixth and seventh decades (McDermot and Shaw, 2008). People have to wait many months to receive their diagnosis of MND (Donaghy, et al 2008), and they have already experienced the degenerative nature of MND that characterises MND (Bolmsjö, 2001). People often retain an active mind but are increasingly unable to move any of their muscles, and death usually occurs within months for progressive bulbar palsy MND, and three to five years for amyotrophic lateral sclerosis MND (MNDA, 2000; Oliver, 2002). Research in the U.K. that focuses on similar areas of interest as my own has focused on care values in MND (Brown, 2003), on whether life is biographically disrupted when living with MND (Locock et al., 2009), and on how people talk about living with MND (Brown and Addington-Hall, 2008). These studies have identified that being diagnosed with MND was an “existential shock” (Brown, 2003), a “biographical abruption” of a previously planned life (Locock, Ziebland, and Dumlow, 2009), and a “fracturing narrative” which tells of loss and fear of the future (Brown and Addington-Hall, 2008). Each of these studies has identified existential concerns for people living with MND. In a study conducted outside the U.K., patients talk about their existential concerns for life and death (Bolmsjö, 2001); though this is the only study identified, more studies may exist. MND is relentlessly progressive with no curative treatment, and the recommended clinical management of MND is palliative care throughout the disease trajectory (Oliver, 2002). However, whether a person receives palliation may be dependent on geographical location in the U.K. (Oliver, 2002), as well as presenting symptoms (MNDA, 2013). In the U.K., the recommendation for care in MND is medical and functional. Those who experience a loss of speech, loss of respiratory function, or are in their terminal phase are referred into the palliative care services (MNDA, 2013). People may prioritise their existential concerns ahead of their medical and functional needs; all people have a need for palliative care services from the time of diagnosis to affirm the meaning of life and death as a normative process (WHO, 2002).

1.2 RATIONALE FOR THE STUDY

The need for this study was apparent from my own personal and professional background: the very emotive experience of being the main carer for my mother living through a relatively short illness trajectory of MND, unable to communicate her needs, wishes and priorities at the end of life, and my role as a community occupational therapist caring for people living with MND. I bring to this study an understanding of being a provider and receiver of care in the community. I understand that focusing on the disease rather than the person is neglecting their individuality. Finlay (2011) argues that phenomenology focuses on issues of interest for therapists and offers valuable information to the profession. As a researcher, I came to this study with a number of issues of concern. The primary concern was to understand the meaning of existence for others when given a diagnosis of MND. I considered how the other issues of concern would be answered by choosing a phenomenological approach which focuses on aspects of existence relating to life and death, embodiment and identity, choice and meaningfulness, belonging and needs, time and space, freedom and oppression (Finlay, 2011). In addition to a phenomenological approach that I understand as a researcher, I bring background experiences to the study.

1.3 HERMENEUTIC PHENOMENOLOGY

The founder of the philosophy of phenomenology was Edmund Husserl (1913/1962), his epistemological method being descriptive phenomenology (Koch, 1995, Finlay, 2011). According to Koch (1995) Husserl understood the person as a mind-body entity existing in the world of objects, asking such questions as: "How do we know what we know?" The unit of analysis is the meaning-given subject, what is shared is the essence of the conscious mind. Meaning is free from the interpreter's view of the world; the data must speak for themselves. To achieve this, Husserl introduced the concept of "bracketing" any prior presumptions that may prevent objective interpretation. Martin Heidegger (1927/1962) recast phenomenology by moving away from Husserl's epistemological method that focused on the essence of the conscious mind (Finlay, 2011). Moran (2000) provides further understanding on what was happening at that time. He states "Heidegger wanted to employ phenomenology as the proper mode of access to the phenomena of concrete human life, factual life, as a way of thinking about human nature that remained faithful to the historical, lived, practical nature of human

experience, to overcome Husserl's predominantly cognitive approach to human being". Heidegger terms human existence as "Dasein" (being-in-the-world, being-there) (Moran, 2000). He asked questions about experiencing and understanding: what does it mean to be a person? The unit of analysis is the experience of the situation and the person; what is shared is history, culture, practice and language. Interpreters participate in making data, with the understanding that the interpretation can only make explicit what is already understood. To achieve this Heidegger introduced the idea of the "hermeneutic circle." While the researcher brings their own background and frames of meaning to the hermeneutic circle of understanding, these cannot be "bracketed", ignored or forgotten as they are contextualised life events (Koch, 1995). The background experiences of supporting my mother in the care context have been brought to consciousness early in the research project to respect what is already understood, to appreciate what experiences remain of concern, and to remain open to new understandings (Finlay, 2011; Geanellos, 1998; Koch, 1995). Because of the nature of the subject under examination, hermeneutic phenomenology offers a sensitive approach to this study, and a way of understanding a person in a wider temporal frame, beyond their disease context. The participant is both the expert and an authority on his or her own life.

1.4 THE PURPOSE AND AIM OF THIS STUDY

The purpose of this study was to gain an understanding of living with MND, receiving health care and the impact on self and identity, in order to contribute to caring policy and practice. The aim was to answer the research question: "What does it mean to be a person living through the illness trajectory of MND?" and to study the phenomenon of existence when given a diagnosis of MND in the context of receiving health care.

1.5 PARTICIPANTS

A maximum variation purposive sample of four people with an accepted diagnosis of MND (all types) was involved in this study. The participants have been recruited from a local neurological centre in the North of the U.K.

1.6 DATA COLLECTION

A hermeneutic position holds that stories are interpretations of life; a story helps us to communicate the unity of our lives and therefore to create our identity (Widdershoven, 1993 in Atkinson, 1998). Atkinson (1998, p.11) states: “a life story narrative may be the most effective means for gaining an understanding of how the self evolves over time or at least seeing the subjective perspective on that”. The participants are given the opportunity to tell their life story, which involves the construction of his or her past, present and anticipated future life (Fischer, 1982 cited in Rosenthal, 1983). The researcher put forward the topic of interest, and provided the participant the opportunity to select which stories they wanted to be included (Rosenthal, 1983; Wengraf, 2001). I have asked each person to recount their unique illness journey from when they first experienced something untoward was happening to them.

1.7 LITERATURE SEARCH

Initially, searches were made for articles published in English since 1980, using the following key words: persons (patient, client and service user), focus (motor neurone disease, MND, amyotrophic lateral sclerosis, ALS, existence, meaning, experience, perspective, view, narrative, story, and stories), services (health care services, MND care services, palliative care, biomedical management) and concepts (self, identity, biographical disruption and repair, hope and burden). The databases used for this research have included Medline, Cinahl, AMED, Psych Info, Evidence Based Medicine Reviews, and Web of Sciences; references used by the other authors in MND; the grey literature (unpublished thesis); and DipEx Org UK (a health experience research group). The exploration of this literature uncovered that the work on the meaning of existence with MND through time was limited. In addition, the exploration of hermeneutic phenomenology enhanced my focus on how the search should evolve to incorporate the concepts of: spirituality, existential, being-in-the-world, being-with-others, temporality, spatiality, thrownness, embodiment, mood, mortality, end-of-life, and lifeworld.

The literature rejected for this study included literature that focused on: ventilation needs, management and experiences; preferences for communication; utilisation of home care services; types of support networks; use of telemedicine; and preferences for wheelchair mobility. It was acknowledged that any one of the rejected topics might feature in the participants' stories, which would involve a return to this literature.

1.8 THESIS STRUCTURE AND CHAPTERS

In addition to this introductory chapter, this thesis contains the following chapters:

Chapter 2 – This chapter begins to provide a background to the study and is divided into two subsections. The first part of this chapter reviewed the objective perspective of the course of motor neurone disease and how it is managed. The second part provides a review of the subjective discourse on living with MND and receiving health care. The argument is that people living with MND are experiencing existential concerns, yet health care focuses on the functional aspects of MND.

Chapter 3 – This chapter provides further background and is also divided into two subsections. The first part of this chapter introduces Heidegger's hermeneutic phenomenology to understand (interpret) what kind of being the human being is. The second part offers a review of the discourse on existential concerns and suffering, and provides a rationale for the purpose and aim of the study.

Chapter 4 – The ontology, epistemology and methodology chapter provides a rationale for using (ontology); it further explores the relationship between the enquirer and the known (epistemology) and considers how this study aims to gain further understanding.

Chapter 5 – The methods used to carry out the research are described.

Chapter 6 – Interpretations and findings are described.

Chapter 7 - Discussion of findings are described.

Chapter 8 - Reflexivity concentrates on my own experience and involvement in this study, on being open to the meaning of others, and becoming a hermeneutic phenomenologist.

Chapter 9 – Conclusions to the study are described.

CHAPTER 2 - MOTOR NEURONE DISEASE

2.1 MOTOR NEURONE DISEASE

This chapter provides an overview of the literature in relation to MND, the management of MND and the available discourses on both. It also provides a philosophical perspective on the meaning of existence, and the existing discourses on existential concerns and existential suffering.

2.1.1 WHAT IS MND?

Motor neurone diseases (MND) are a group of age-related neurodegenerative disorders of unknown aetiology. Motor neurons transmit electrical signals from the brain (upper motor neurons) and the spine (lower motor neurons) to muscle groups in the body to generate movement. The upper motor neurons situated in the higher brain area (motor cortex) send signals down the spinal cord to connect at different junctions with the lower motor neurons. These in turn send signals to the muscles to initiate movement of the arms and legs (Talbot and Marsden, 2008). In motor neurone disease, also known as amyotrophic lateral sclerosis (ALS) motor neurons progressively degenerate and eventually die (Talbot and Marsden, 2008).

2.1.2 AETIOLOGY

Little is understood about the causes of MND from studying the environment or the life histories of people living with MND. Some of the suggested risk factors include exposure to insecticides, heavy metals, electromagnetic radiation and solvent, a history of fractures and other traumas, athleticism, and military service; however, these risk factors remain unconfirmed. Talbot and Marsden (2008) state only 2-3% of patients with familial MND carry mutations in the gene superoxide dismutase (SOD1), in 90% of patients, it is obvious that they do not have genetic causes for their disease. It remains a possibility that genetic variations, acting together, increase the risk of developing MND (Talbot and Marsden, 2008). Other genes thought to be involved are TDP-43 and FUS (Oliver, 2002). Of course it may be

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a concern for people diagnosed with MND whether they risk passing MND onto their family members (Bolmsjö, 2001).

2.1.3 EPIDEMIOLOGY

In the most recent epidemiological study carried out in the U.K. Alonso, Logroscino, Jick and Hernan (2009) used the general practice research data base between the period of 1990 and 2005, which recorded 830 new cases of MND (360 in women; 470 in men). Alonso et al, confirm the incidence rate in the U.K. is 2.6 per 100,000 persons per year in women and 3.9 in men, with a lifetime risk of MND being higher for men than women: one in 472 for women and one in 350 in men, the average age of onset for both sexes peaking at 75-79. Talbot and Marsden (2008) state the incidence rates highlight the fact that MND is a relatively rare disease, which means that health care professionals do not often encounter people living with MND. For example, one in 1000 death certificates record MND as the cause of death, in comparison to stroke which will affect 1-3, and cancer (all types) which affects 1-4. There is no evidence to suggest MND is becoming more common, except that increasing life expectancy will impact on the number of people being diagnosed with MND.

2.1.4 TYPES OF MND

At the time of diagnosis a person learns that MND is a life-threatening disease with no known cure (Leigh et al., 2003); they are offered the drug Riluzole which is shown to increase survival of up to 3-4 months (McDermot and Shaw, 2008). A person may learn at the time of diagnosis that they have one of four types of MND. The different types include Amyotrophic Lateral Sclerosis (ALS); Progressive Bulbar Palsy (PBP); Progressive Muscular Atrophy (PMA); and Primary Lateral Sclerosis (PLS) (Talbot and Marsden, 2008; MNDA, 2000; 2013) (see table 1 below for prevalence, areas affected, signs and symptoms, and prognosis). ALS is the most common MND (Forbes, Colville and Swingler, 2004; Talbot and Marsden, 2008).

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TABLE 1 TYPES OF MND (TAKEN FROM MNDA 2013)

Type of MND	Prevalence	Areas affected	Signs and symptoms	Prognosis from onset of symptoms
Amyotrophic Lateral Sclerosis (ALS)	This is the most common form.	Upper and lower motor neurone involvement.	This form of the disease is characterised by weakness and wasting in the limbs. Notable signs are tripping when walking or dropping things.	Life expectancy is from two to five years.
Progressive Bulbar Palsy (PBP)	Affects about a quarter of people.	Upper and lower motor neurones.	Symptoms may include slurring of speech or difficulty swallowing.	Life expectancy is between six months and three years.
Progressive Muscular Atrophy (PMA)	Affects a small proportion of people.	Lower motor neurones only.	Early symptoms are weakness or clumsiness of the hands.	Most people live for more than five years.
Primary Lateral Sclerosis (PLS)	A rare form of MND.	Upper motor neurones only.	Causing mainly weakness in the lower limbs. People may experience clumsiness of the hand or speech problems.	Lifespan could be normal. This may develop into ALS.

2.1.5 SIGNS AND SYMPTOMS

There is a remarkable degree of variance in the presentations of MND (Talbot and Marsden, 2008). Each MND has varied symptoms characterized by rapidly progressive muscle weakness (atrophy), fasciculation, muscle spasticity, dysarthria, dysphagia and dyspnoea (Leigh et al., 2003). A person receiving their diagnosis of MND will already have experienced the changing levels of ability that characterise MND (Bolmsjö, 2001). They may have been dropping things or tripping over, and they may have lost their speech (MNDA, 2000). For the purpose of this study, a maximum variation purposive sample of four people with an accepted diagnosis of MND (all types) would provide a range of experiences of signs and symptoms as follows:

MUSCLE WASTING

Rapid progressive wasting in the muscles, otherwise known as muscle atrophy, sets in because the lower motor neurons transmit a long process (termed axon) to the muscle. When the contact between the neuron and the muscle dies or is broken, the muscle becomes thinner (termed muscle wasting or atrophy). The muscle may lose its normal tone or become floppy; muscle weakness and loss are inevitable (Talbot and Marsden, 2008).

FASCICULATION

The term fasciculation is the term used to describe a small, local, involuntary muscle contraction. When lower motor neurons become damaged, the connected muscle experiences wasting and weakness. Muscle wasting associated with chaotic flickering of muscle is termed fasciculation, a sign that the muscles have lost their nerve connection (Talbot and Marsden, 2008).

MUSCLE SPASTICITY

The function of the upper motor neurons is to initiate movement from the brain, down the spinal cord to the lower motor neurons. If the upper motor neurons degenerate, the consequence is that the lower limbs become stiffer (the term for this is spasticity). The loss of function in MND/ALS is as a result of a mixture of stiffness and weakness of muscle (Talbot and Marsden, 2008).

DYSARTHRIA

Difficulty speaking is called dysarthria. In MND this is caused by a mixture of lower motor neuron degeneration resulting in the tongue becoming weak and wasted. Speech sounds “flabby” due to upper motor neuron degeneration resulting in stiffness and slowness of the tongue (Talbot and Marsden, 2008).

DYSPHAGIA

Difficulty swallowing is called dysphagia. Depending on the pattern and MND diagnosed, the muscles that are involved in chewing and swallowing become slower, stiffer and weaker. People with PBP MND are likely to experience these symptoms early into their trajectory (Talbot and Marsden, 2008).

DYSPNOEA

Difficulty with breathing is called dyspnoea. Normal breathing involves the activation of the muscles of the chest wall and also the diaphragm; in MND any of these muscles may be affected, resulting in disturbances in breathing. Most significantly, for the majority of

patients living with MND, it is the result of progressive loss of strength in the respiratory muscles that causes shortening of life (Talbot and Marsden, 2008).

2.1.6 FEAR/BEREAVEMENT/ACCEPTANCE

Before their diagnosis of MND, patients may have fears of tests, diagnosis, disease progression, death and dying (Boraiso, Sloan and Pongratz, 1998). People diagnosed with MND are likely to go through the stages of bereavement, experiencing shock, denial, anger, guilt, and depression (Talbot and Marsden, 2008). They may already understand that “MND leaves people locked in a failing body; unable to move, walk or talk but the mind usually remains alert” (MNDA, 2008, p.2). Clayton, Butow, Tattersall, et al., (2005) recommend that all people diagnosed with advanced progressive life-limiting illness should be given the opportunity to discuss prognosis, including life expectancy, how the illness may progress, future symptoms and effect on function, and end-of-life issues. They also recommend that patients should be actively involved in decision-making to increase the sense of control over their life (Talbot and Marsden, 2008).

2.1.7 SUMMARY

This section has brought forward the devastating nature of MND, and the understanding that MND has multiple symptoms and effects. MND is a rare fatal neurological disease. It remains a scientific puzzle as to why people develop MND in the later stages of life. The MND trajectory may be months or years; this all depends on the type of MND. Because MND mimics other illnesses, it can take up to 15.6 months for a diagnosis to be made (Donaghy et al, 2008). This next part of background/literature will review the objective perspective on the management of MND.

2.2 THE MANAGEMENT OF MND

This section of the thesis will take a look at an objective focus on health care delivery, moving on to the nature of reality for people diagnosed with MND receiving health care in the 21st century.

2.2.1 PHILOSOPHICAL PERSPECTIVE

“Greek physicians had observed the body cannot be treated without at the same time treating the soul. It is further suggested that perhaps even this is not enough, that it is impossible to treat the body without possessing knowledge concerning the whole of being” (Gadamer, 1993, p.793).

The diagnosis of illness is determined from knowledge gained within the natural sciences; however, once given a diagnosis, a person with an illness then becomes a social state of affairs and a psychological moral state of affairs (Gadamer, 1993). What Gadamer is referring to here, is that once a person is diagnosed they become involved in a social system, like the U.K. health care system. Gadamer points out how people used to be reliant on their family doctor to provide social, psychological, and moral support. Today, he states we are often deprived of our G.P. providing such levels of support. We are more likely to be reliant on practical experiences of clinicians, who see their patient in the clinical stage, and therefore do not understand the patient and their history, and care becomes “unavoidably abstract” (Gadamer, 1993, p.21). Gadamer argues that health care practice has become objectified in terms of multiplicity of data and that personhood is lost. Though Gadamer is referring to the health care practice of some thirty years ago, his insight has meaning for health care practice in the 21st century. The patient diagnosed with MND is a prime example. First, the patient visits their G.P. because they have noticed something untoward is happening to them. Second, they undergo a number of clinical investigations (brain scan, nerve testing, breathing tests) and all of this information about a person is collated onto a computerised system. All the relevant data is then applied to the person presenting to the consultant with the disease. Gadamer questions whether the unique value of the person is also acknowledged in this process.

2.2.2 MULTIDISCIPLINARY TEAM

Not through choice, people living with MND require help to manage their symptoms from a multidisciplinary team of health care professionals (MNDA, 2011). Thomas (2010) refers to patients receiving health care in the U.K. as being involved in a different social system (the NHS). Involvement in this social system means receiving health care from a range of health care professionals working in a variety of settings (Oliver, 2002). Oliver highlights the number of professional services that may be involved in the management of MND: 1. Neurology services; 2. The MNDA Care Centres; 3. Research centres; 4. Community service;

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5. Palliative care services. This brings into question whether people receiving health care from so many different services are experiencing continuity of care. Patients with MND receiving health care report deficiencies in the organisation of health care services (Brown, Lattimer and Tudball, 2006). People living through their illness trajectory may receive care from a number of the multidisciplinary team of HCPs (see Table 2 below):

TABLE 2 MULTIDISCIPLINARY TEAM (TAKEN FROM MNDA, 2011)

Key Professionals	Ideal/Co-options/Access to
<ul style="list-style-type: none"> • Care Centre/Neurology Link • Care Manager • Dietician • Occupational Therapist (OT) • Palliative Care • Physiotherapist (PT) • Respiratory Nurse • Social Worker (SW) • Speech and Language Therapist (SALT) 	<ul style="list-style-type: none"> • Carer support • GP • Community Nurse • Rehabilitation Consultant • Gastroenterologist Team • Continuing Care Assessor • Pharmacist • Psychologist • Respiratory Physician • Wheelchair Service • Housing • Benefits Advisor • Care Agencies • Spiritual Support
←MND Association→	

2.2.3 PROFESSIONAL DISCOURSES ON CARING FOR PEOPLE LIVING WITH MND AND MS

How professionals respond to people living with multiple sclerosis (MS) and motor neurone disease (MND) has already been explored (Carter, McKenna, McLeod and Green, 1998). The hypothesis of the study was that MND as a terminal illness with a generally short, aggressive and unrelenting course, would evoke more negativity from health professionals than MS, where the two main clinical subcategories, chronic progressive and relapsing-remitting, often follow a protracted course (Carter et al., 1998). The study sample of health care professionals included medical specialists, GPs, speech language therapists, nurses, occupational therapists, physiotherapists, social workers and dieticians. The study found that health professionals were more negative towards patients with MND than patients with MS. This is because of what they could not offer, and depended on whether they are confident managing patients. The authors state that the difficulties experienced by health care professionals are understandable because of MND patients' short prognosis, impending death and

communication problems. In caring for patients with MS, issues which were considered as difficult were: changes in patients' affect, cognition and personality which resulted in their becoming more demanding. Management issues for both MND and MS patients were similar and included: resource issues in the face of progressive disability and the effect this has on the patient; health care professionals found it difficult to remain positive; interdisciplinary team problems; difficulties regarding patient care. In addition, the findings highlighted that hospital-based health professionals felt more negative about working with MND patients than those based in the community. As already pointed out, MND is a rare neurological disease and health care professionals may not have experience of working with patients with MND. The aim of this study is to understand individual experiences of living the course of MND over time, plus the actions of clients, families and health care professionals to manage that course, notwithstanding attitudes.

2.2.4 PROFESSIONAL PARADIGM

All health care professionals have their own professional paradigms and work within shared policy frameworks and practice guidelines. In the management of MND, Brown (2003) found that "professionals appreciate the debilitating effects of MND, but their practice prioritises their functional roles over emotional support. This situation is often created through external constraints but leaves professionals in a constant state of tension" (p.215). Both Carter et al. (1998) and Brown (2003) found that health care professionals were unsatisfied with the care they delivered to patients with MND. Finlay (2001) points out the constant struggle for one professional group, occupational therapists, to manage the tension between their beliefs and practice. Central to occupational therapy as a profession is the underpinning of humanistic, holistic and client-centred values (Finlay, 2001). Finlay (1997, p.53) points out that the concept of self is central to the humanistic approach and adds: "each of us is unique and made up of our own individual thoughts, feelings, behaviours, attitudes, bodies, past experiences. Thus we have self-awareness, a self-identity, and a sense of our self as continuing – there is only one of us". Holistic occupational therapy assessment involves understanding the whole of a human being, and not just a sum of parts (Popper, 1957 in Finlay, 2001). Exploring in more depth the professional paradigms of other professional groups may reveal similar issues, where the focus is on the disease and not on the uniqueness of each individual and their needs, which may result in a professional's beliefs and practice

being in tension (Finlay, 2001; Brown, 2003). The next section will review the relevant policy framework and practice guidelines in MND.

2.2.5 POLICY FRAMEWORK

Health care professionals in the U.K. are guided by policy frameworks and practice guidelines, which determine how their care is delivered. The policy framework and practice guidance relevant for the care and treatment in MND are NSF for Long Term Neurological Conditions (LTnCs) (DH, 2005); MNDA Best Practice Guide (2011) and MND Services are provided along the Year Pathway (MNDA, 2013). As a result of medical management of long-term conditions, many people have extended life expectancy, and “terminal diagnoses” are now referred to as “long-term” conditions (Pearson, 2010). The NSF for LTnCs (2005) was introduced to guide health care professionals in the treatment and care of patients with a life-threatening condition, from diagnosis to end of life. The NSF for LTnCs (2005) broadly categorises long-term neurological conditions as (see Table 3). This table is presented in the thesis to indicate how health care professionals are guided in the knowledge that the deterioration of MND can be rapid, and therefore, to highlight the existential concerns these people must face.

TABLE 3 LONG-TERM NEUROLOGICAL CONDITIONS (TAKEN FROM DH, 2005)

NSF for LTnCs (2005)	Example
Sudden onset conditions	Acquired brain injury or spinal cord injury, followed by a partial recovery. (Note: stroke for all ages is covered in the NSF for Older People)
Intermittent and unpredictable conditions	Epilepsy, certain types of headache or early multiple sclerosis, where relapses and remissions lead to marked variation in the care needed.
Progressive conditions	Motor neurone disease, Parkinson’s disease or later stages of multiple sclerosis, where progressive deterioration in neurological function leads to increasing dependence on help and care from others. For some conditions (e.g. motor neurone disease) deterioration can be rapid. (Note: dementia for all ages is covered in the NSF for Older People)
Stable neurological conditions	Stable neurological conditions, but with changing needs due to development or ageing, for example post-polio syndrome or cerebral palsy in adults (DH 2005).

2.2.6 ELEVEN QUALITY REQUIREMENTS

To support those receiving long-term care in the community, health care professionals are guided by the NSF LTnC 11 quality requirements, which include:

1. Person-centred services
2. Emergency and acute management
3. Early recognition, prompt diagnosis and treatment
4. Early specialist rehabilitation
5. Community rehabilitation and support
6. Vocational rehabilitation
7. Provision of equipment and adaptations
8. Provision of personal care and support
9. Palliative care
10. Supporting family and carers
11. Caring for people in hospital or other health or social care settings (DH 2005).

The quality requirements 1, 3, 8 & 9 of the NSF for LTnC are relevant to the focus of this study and will be discussed in relation to the evidence.

QR1 PERSON-CENTRED CARE

The tradition of patient-centred care in health started in the 1950s. The focus of care was on the medical management of disease, rather than the illness (Groene, Lambards, and Klazinga et al, 2009). This raised concerns and initiated calls for a more holistic bio-psychosocial model of health (Ballint, 1969 cited in Groene, et al., 2009). Providing a person-centred service is a core theme that runs through the NSF for LTnCs (DH, 2005). The Institute of Medicine (IOM) (2001) defines patient-centred care as “providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions” (IOM, 2001, p.40).

In Little, Everitt and Williamson’s (2001) quantitative study, 824 participants were asked to complete a pre-consultation questionnaire of their preferences for patient-centred consultation in general practice. The sample of Little et al. came from only three surgeries, and the authors state the surgeries reflect a range of practices, including the deprived urban inner city, cathedral city, and market town. They identified three key domains for patient centeredness to be included: communication, partnership, and health promotion. Little et al.’s findings were a conceptualisation of the National Service Framework for Older People (DH, 2001). Stewart (2001) calls for a global definition of patient-centred care, as she states that patient centeredness is becoming a widely used but poorly understood concept in medical practice.

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Stewart's definition emphasises exploring the patients' main concerns; emotional and information needs; finding a common ground; and enhancing the continuing relationship between patient and doctor. Clearly this definition is focused on the patients' physical and psychological concerns, and on building a relationship similar to the practice in occupational therapy which embraces a philosophy of respect for and partnership with people receiving services (Sumsion 1999). Law, Baptiste and Mills (1995) describe some key concepts of occupational therapy in their client-centred approach: autonomy/choice; partnership/responsibility; enablement; contextual congruence; accessibility; respect for diversity. Sumsion and Law (2006) defined five new core elements of client-centred practice: power; listening and communication; partnership; choice; and hope. The Picker Approach to assessing patients, which has eight dimensions to patient-centred care, relates to patients receiving care in a variety of settings (Jenkinson, Coulter and Bruster, 2002). A review of the definitions for person centeredness (see Table 4) highlights that the variance in definitions depends on professional paradigms. What this table highlights at a glance is the fact that only Jenkinson et al (2002) suggest emotional support and alleviation of fear and anxiety is necessary for person centredness, and in the acute setting.

EXISTENTIAL LOSS IN THE CONTEXT OF MOTOR NEURONE DISEASE: A HERMENEUTIC PHENOMENOLOGICAL STUDY**TABLE 4: PERSON-CENTREDNESS**

Professional body/author	Concepts of person/client-centred care							
Medical/ Institute of medicine (2001)	Respectful and responsive to patients' preferences, needs, and values	Partnership among practitioners, patients, and families	Patients have education and support					
Medical/ Little et al. (2001)	Communication	Partnership	Health promotion					
Medical/ Stewart (2003)	Exploring the patients' main concerns	Emotional needs	Information needs	Finding common ground	Enhancing and continuing relationship between doctor and patient			
Occupational therapy/ Law et al. (1995)	Autonomy/ Choice	Partnership/ responsibility	Enablement	Contextual congruence	Accessibility	Respect for Diversity		
Occupational therapy/ Sumsion and Law (2006)	Power	Listening and communication	Partnership	Choice	Hope			
Acute care / (Jenkinson et al., 2002)	Access	Respect for patients' values, preferences and expressed needs	Coordination and integration of inpatient services	Information, Communication and education	Physical comfort	Emotional support and alleviation of fear and anxiety	Involvement of family and friends	Transition and continuity after discharge

QR3 EARLY RECOGNITION, PROMPT DIAGNOSIS AND TREATMENT

This section focuses on early recognition of neurological symptoms in primary care. People suspected of having a neurological condition are to have prompt access to specialist neurological expertise for an accurate diagnosis and treatment as close to home as possible (DH, 2005a; COT, 2006; MNDA, 2011). It is acknowledged that early diagnosis can greatly reduce stress and anxiety for patients and their families; providing information and advice in the early stages can make a difference to the way the family copes with the situation. Specialist practitioners with specific knowledge of the condition should be available to offer timely access to therapy and support in the community, if necessary before a diagnosis is confirmed (COT, 2006). Many people receive a diagnosis on average 15.6 months from symptom onset, less in bulbar onset (Donaghy, et al2007). The role of the consultant is to restore equilibrium, and be involved with human beings who must be “treated” (Gadamer, 1975). A person is reliant on the consultant “knowing how to distinguish” MND from other neurological presentations, and this may cause a delay in diagnosis.

The biomedical nature of care is based on providing good symptomatic management. This includes management of percutaneous endoscopic gastrostomy (PEG), nutritional support, and ventilatory care with non-invasive ventilation, and palliative care introduced before the terminal stages and after careful discussion with the patient and their carer(s) (Howell and Orrell, 2002). Anxiety and depression may or may not follow a diagnosis of MND. To prevent anxiety and depression drugs are recommended (Howard and Orrell, 2002). McDermott and Shaw (2008) provide details (see Table 5 below) on how to manage the symptoms of MND from a standard clinical perspective. This table shows the multiple symptoms of MND additional to what has been reported elsewhere; it demonstrates why biomedical management of MND is essential, and illustrates the reason behind the introduction of the MND Care Centres and Networks across England, Wales and Northern Ireland in 1990 (MNDA, 2013).

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TABLE 5 MANAGING SYMPTOMS (TAKEN FROM McDERMOTT AND SHAW, 2008)

Symptom	Drug
Difficulty swallowing saliva	Hyoscine patch*, atropine, amytriptyline, glycopyrrolate, botulinum toxin injection of salivary glands*, parotid irradiation*, portable suction device.
Thick saliva or bronchial secretions	Mucolytics such as carbocisteine (250-750 mg three times a day), nebulised. Saline with or without β receptor antagonosis or anticholinergics. Ensure patient is not dehydrated, avoid mouth breathing.
Cramp	Quinine sulphate, physiotherapy, magnesium, carbamazepine, verapamil.
Spasticity or jaw spasm	Physiotherapy†, baclofen, dantrolene, tizanidine, clonazepam.
Emotional lability, depression	Amytriptyline, selective serotonin reuptake inhibitors such as citalopram.
Urinary frequency	Amytriptyline, oxybutinin, detrusitol.
Constipation	Movicol, lactulose, docusate, senna, co-danthromer Ensure patient it not dehydrated; assess fibre intake.
Choking (laryngospasm) or respiratory distress	Lorazepam (0.5-2.5 mg sublingually) for short spells. Breathing space kit is available by request
Severe and prolonged dyspnoea	Oral morphine 2.5 mg four to six times a day for longer spells. Subcutaneous morphine 0.5 mg/hr and titrate

QR8 PERSONAL CARE AND SUPPORT

Health and social care professionals should work together to provide the care and support a person needs for independent living. The College of Occupational Therapy (COT) (2005) recommend identifying good practice as appropriate training for staff in the management of neurological conditions, and providing equitable access to services and assessments.

Equitable access to services and assessments may include; identifying the need for community care services, adult care service, and for fully funded NHS Continuing Care. This guidance is not prescriptive, which means that individual services may differ, depending on their resources.

The patient in need of NHS Continuing Care will have complex physical and psychological requirements. Physical problems include dysarthria which may cause weakness and wasting of the tongue, lips, facial muscles, pharynx and larynx; pain may be caused by muscle cramps, spasticity, stiff joints, skin pressure, constipation; dyspnoea, which is caused by weakened

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respiratory muscles, affects about two thirds of all patients eventually; dysphagia and malnutrition are caused by weakness and paralysis of the bulbar muscles (MNDA, 2000). Psychological symptoms may include the following: fears of choking to death or fighting for breath, loss of independence and dignity, increasing dependency and becoming a burden, inability to cope, and loss of control. In addition, fear of the unknown, death and the process of dying, denial, anger, sadness, depression, emotional lability, anxiety, depression, adjustment, and sleep disturbances (MNDA, 2000). The MND Association (2000) acknowledges that people with MND and families often suffer psychological and emotional distress because of the significant challenges of coping with loss and living with change. As they state that much can be done to alleviate distress, such as helping patients to adjust.

Helping people to adjust and use their coping skills was the major focus of an Australian study of patients living with amyotrophic lateral sclerosis type MND. King, Duke and O'Connor (2009) used a grounded theory approach. Their aim was to present a model that explores the dimensions of change and adaptation for people living with ALS type MND. The participants were recruited from the MNDA in Victoria, Australia. Instead of using a traditional approach to theoretical sampling, because of the limited population of people living with MND in Australia, 2-4 in 100,000, theoretical sampling was achieved by collecting further data about emerging themes in subsequent interviews. The findings represent a comprehensive account of changes experienced by a person with ALS-type MND, such as first noticing changes in finger movement and ability to control emotions, which are characteristics of the early signs of MND. King et al. (2009) also identified the progressive nature of MND: "lives began to revolve around making decisions about how to live with the progression of the disease and deteriorating abilities" (p.753). This understanding helped the authors to design an ongoing change and adaptation model for decision-making. King et al. state this model may be a valuable tool to use in the clinical setting. This study brings to the forefront how people living with MND have to make decisions on their changing circumstances, and how they need to adapt to an evolving situation and to diminishing physical abilities. The tool has been designed for people living with MND in Australia to enable them to take control of their lives. The authors argue that people living with MND in the U.K. feel that they do not have any control over their disease (Sakellariou, Coniface, and Brown, 2012). It is suggested that this Australian study has something to offer to the U.K.

QR9 PALLIATIVE CARE

There is a definite contradiction in the management of people living with MND as to when they are to receive palliative care. The NSF for LTnCs (2005) guidelines state that people in the later stages of long-term neurological conditions are to receive a comprehensive range of palliative care services when they need them to control symptoms; health care professionals have to offer pain relief and meet their needs for personal, social, psychological and spiritual support, in line with the principles of palliative care (DH, 2005). Oliver (2002) states that all people living with MND should receive palliative care from the time of diagnosis, regardless of the type of MND. In addition to this, Oliver suggests that life and death discussions need to begin at the time of diagnosis and continue throughout the illness trajectory. He also suggests that ongoing discussions need to be held with the patient, their family and health care professionals. Oliver (2002) provides hospice level guidelines which have been based on the World Health Organisation (2002) key principles of what constitutes the holistic needs of those living with a terminal diagnosis. Oliver suggests that care should focus on the physical, spiritual, psychological, and social needs of the patient and be undertaken by a multidisciplinary team. The physical aspects of care are to take into account that there are many different symptoms that should be considered, some directly related to the disease process, others to the effects of muscle weakness (Oliver, 2002). The spiritual aspects of care should acknowledge that a person is facing increasing disability and the possibility of an early death, which may prompt them to consider the deeper meaning of life and death. Oliver (2002) states that spiritual concerns

May not necessarily be in the form of organised religion, but in terms of ‘natural religion’, with concerns over the future. Time may be needed to talk about these issues, and it is easier to do so while speech is reasonably intact, as to discuss these deep issues by means of an electronic communication aid can be very difficult (Oliver, 2002, p.74).

Psychological aspects of care involve acknowledging fears of the diagnosis, fears of dependency and disability, and fear of dying. Oliver recommends that all professionals who are involved in caring for people with MND should be willing to explore these fears if and when necessary. Oliver also recognises that people living with MND are part of a wider social group of family and friends, and that they will also be affected by the progressive nature of MND and have similar concerns. In the next section will review practice guidelines specific to the management of MND.

2.2.7 PRACTICE GUIDELINES

Health care professionals in the U.K. are guided by practice guidelines (MNDA, 2011, 2013). The Motor Neurone Disease Association (MNDA) (2011) has reviewed the NSF for LTnCs' eleven quality requirements (DH, 2005) and implemented a Best Practice guide in MND. The starting point of this guidance states: "from diagnosis, an individual's spiritual and emotional needs should be addressed alongside medical and practical considerations, but this may be of paramount importance to those affected by MND in the later stages of the disease" (MNDA, 2011, p.8). Health care professionals have recognised that people living with MND require a proactive approach to care and treatment. The MNDA have introduced the 'Services required along the Year of Care pathway' (MNDA, 2013): though it is not clear why this is directed towards the first year of the illness trajectory, this pathway offers guidance for health care professionals to manage a patient living with MND. The care pathway recommends referral to different health care services based on milestones (generic needs at and post diagnosis). The needs based on loss of function include use of arms; ability to walk; ability to manage personal hygiene and care; speech; ability to swallow; respiratory function; cognitive function; and palliative care prior to death (Appendix G). What is clear from this pathway is that the care delivered is very much focused on the management of the medical and functional needs of people living with MND, and not their spiritual and emotional needs. Where palliative care input is mentioned in the care pathway, these are highlighted in red. Referral to the palliative care services is mentioned for those who have experienced a loss of speech, respiratory function, and are nearing their end of life. This pathway does not identify the need for a person diagnosed with MND to be put onto the palliative care pathway at the time of diagnosis. This care pathway recognises the variable presentations of MND, and it states: "Refer to allied health professionals according to presenting symptoms and need, and to MND or neurology specialist nurse/service or regional MND Care Centre. Refer to the MND Association". The care pathway does not acknowledge the significance of MND as an "existential shock" (Brown, 2003), a "biographical abruption" (Locock, et al., 2009) at the time of diagnosis, and loss of movement as "existential suffering" (O'Toole, 2011). The care pathway does suggest that practical, emotional, social and financial support is available via the association throughout the disease; people are able to contact an advisory line for this

support. The emphasis on the MND association providing emotional support takes away the responsibility from health care professionals.

2.2.8 SUMMARY

This section of the thesis has demonstrated that MNDA care guidelines in the U.K. suggest care focus in the first year of the illness trajectory is on loss, such as loss of function, arms, ability to walk, personal hygiene and needs, speech, ability to swallow, respiratory function, and cognitive function. Only if a person is unable to speak, or has breathing difficulties, or is nearing their end of life, do the guidelines recommend referral into the palliative care services (MNDA, 2013). Palliative care professionals have specialist knowledge and skills for helping people to cope with the emotional, social and spiritual aspects of life-limiting illness, and therefore, do not just focus on the person and their functional loss. Gadamer's concern for the unique value of a person in the process of delivering objectified health care may be justifiable in this context. The next part of the thesis will review the current available evidence on living with MND.

2.3 DISCOURSE ON LIVING WITH MND

2.3.1 INTRODUCTION

This part of the thesis will explore the available existing literature on living with MND. The findings reported here are grouped as follows: psychological impact; physical and social impact; biographical abruption, disruption and repair.

2.3.2 PSYCHOLOGICAL IMPACT OF MND

Concerned with how the psychological impact of MND is managed, Hogg, Goldstein and Leigh (1994) carried out a postal survey. The findings taken from 59 individuals who completed a self-report form indicated that the effects of MND on everyday functioning accounted for incidence of depression and low self-esteem. Hogg et al. (1994) make the following recommendations: a person undertakes a life review and person is helped to put personal affairs in order and to focus on grieving. The authors are calling for health care

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professionals to recognise a person has a past before their diagnosis of MND. In addition, they are calling for health care professionals to recognise that a person diagnosed with MND has experienced considerable loss, and, therefore, people are naturally going through the grieving process. Similarly, McLeod and Clarke (2007) were concerned that the management of MND focuses on the physical impact and that the psychosocial aspects were “accorded secondary importance” (p.4). The results were presented under the following headings: quality of life; psychological functioning; depression, anxiety and distress; social support and social disability; hopelessness and suicidal ideation; life-sustaining treatment; positive coping; hope, meaning and spirituality. Following the review, McLeod and Clarke (2007, p.4) recommend: “Depression and other expressions of distress require recognition and treatment. Issues of hope, spirituality and life and death also require attention in clinical practice”. There is no available evidence to suggest people are receiving psychological support in MND. The next part of this thesis will review people’s experiences of living with MND in the U.K.

2.3.3 PHYSICAL AND SOCIAL IMPACT OF MND

In a qualitative study, Hughes, Sinha, Higginson, Downe and Leigh. (2005) were interested in the physical and social impact of MND, recruiting 9 people living with MND, 5 caregivers and 15 HCPs. The purpose of the study was to understand people’s experiences in order to generate ideas for developing policy and practice in MND health, social and palliative care. The research questions asked included: What are the lived experiences of people affected by MND? What are people’s experiences of care? What is the recommendation for improvements to care? The study made a number of valuable findings in relation to the present study. Firstly, the authors note that their findings have resonance to social theory, in terms of the MND disrupting biographies, the coping strategies used by the participants involved reflecting on the past, adapting to the present, accepting help to cope with the future. Secondly, this study identified that people with MND may conceal their disease, and sometimes their carers would restrict the information available to people with MND to protect their partner from distress and upset. Thirdly, views on health care related to people having difficulty accessing services and entitlements, and health professionals’ lack of knowledge of MND. Hughes et al.’s study was carried out before the implementation of a number of policies, such as the NSF for LTnC (DH, 2005) and the Mental Capacity Act (2005) (DCA, 2007a), and also before the introduction of MNDA Care Centres throughout the U.K. The

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question would be whether these guidelines, directives and specialist centres have improved the care and treatment for people living with MND. The aim of Hughes et al.'s study was to give voice to people's experiences of MND in order to improve services. The authors make recommendations for other research to apply theoretical approaches to studying the experiences of patients living with MND. The findings of Hughes et al. influenced the choice of using hermeneutic phenomenology, because their findings suggest that MND does disrupt biographies (past, present and future).

2.3.4 MND AS A BIOGRAPHICAL ABRUPTION

Hughes et al. (2005) found that living with MND does disrupt an individual's biography (past, present and future), though this was not the major focus of their study. In contrast, Locock, Ziebland and Dumelow (2009) found that MND greatly impacts on people's lives in the following way:

As well as accounts of biographical disruption, we identified a distinctive sense that the diagnosis is a 'death sentence' and life is already over, which we term 'biographical abruption'. We also found instances of biographical repair, as participants sought to make sense of their remaining life, restore normality and control, and find new meaning and identity (p.1043).

Locock et al. state that their findings correlate with the concepts of "existential shock" (Brown, 2003) and the "fracturing" narrative (Brown and Addington-Hall, 2008). Many of the people involved in the Locock et al. study were video recorded, and their stories can be viewed on the healthtalkonline.org (See Excerpt below). The stories online are separated into first symptoms: possible causes of MND; work and career; immediate reactions to MND; support groups and meeting others; philosophy; attitudes to life and messages to others. In terms of health care, people spoke of treatment/interventions: medication, trials, research; PEGs, RIGs and ventilation; complementary therapies and alternative therapies; physical therapy and exercise (Locock, et al., 2009). The excerpt taken from Michael– (Interview 29, healthtalkonline.org) is presented below to illustrate how he felt his world had collapsed and he was left feeling like there was no hope:

It was quite devastating, to be honest. I guess I knew before they told me, in so much as they came round to do their rounds in the morning - and they were lovely [laughs], don't get me wrong, they were very nice and I have no complaints about how or what they did. But knowing what they had to tell me, they said they had the results back

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and wondered what time my wife would be able to come down. I said, "It's obviously bad, then, because you, you know, you feel I need someone to lean on to be able to give me that." And, unfortunately, for them I am a sales person, have been for many years, and consider myself quite good at what I do. And I'm pretty good at spotting a fib when I see one [laughs]. "No, no, it is okay, we just, and we do not want to have to explain everything twice." The bullshit alarms were going off and I just, I knew. I phoned Sam. Bless her, what she must have gone through I do not know. I was in a state of near hysteria. She drove up - dropped everything, drove up. Then they called us in and told us [sighs]. As he put it, it was the worst possible diagnosis as a neurosurgeon. So then, hmm, the specialist and the nurses and - and as I say they were great - the news they delivered was, mm, crushing, devastating. I felt my whole world collapse...in an instant really, wasn't it? [Turns towards wife] It just couldn't have been real, couldn't be real. To be told, "There is no cure. There's nothing that we can do for you. There are; there are some relatively new tablets which we can prescribe for you. They do not cure it. They may slow down its progress." The - how was it put? The jury was still out on it. They would not know how long people who were already taking that drug would have taken to degenerate, had they not have been on it. That was [pause] very hard to come to terms with. "There is nothing, there is no cure." It almost feels like, initially the very first thing that's ripped away from you is hope. That's pretty hard. So for anybody with a condition like this, that is one of the hardest things to come to terms with (www.healthtalkonline.org).

This is the story of a young family man's immediate reaction to being diagnosed with MND. Locock et al.'s findings demonstrate the value of giving people a voice that is easily accessible for those using the World Wide Web. Not all people access information in this way. Locock et al.'s findings have provided an understanding of the effect of MND on lives and future plans and projects. In their narratives, they talk about the medical and practical care they received.

2.3.5 NARRATIVE TYPES (PLOTLINES)

Other researchers also explored the experiences of people living with MND. Brown and Addington-Hall (2008) invited 13 people to be interviewed at three monthly intervals over a period of 3 months. The study's aim was to explore patient experiences and how they talk about living with MND. The authors analysed their data by focusing on the "plot" or form of the narrative, in a way that is similar to the work of Frank (1995). They identified four narrative types (plotlines):

1. Sustaining narratives focus on keeping positive with life and remaining active and engaged.

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2. Preserving narratives focus on continued existence and fighting death.
3. Enduring narratives tell of quiet suffering in the face of death.
4. Fracturing narratives tell of loss, breakdown of self, fear of the future and denial of reality (Brown and Addington-Hall, 2008, p.204-5).

The authors felt the four narrative types can help health care professionals understand what it is like to live with MND. Rolls, Payne and Brown (2009, p.7) pointed out that, where analysis focuses on the structure of narratives, it can run the risk of “subsuming an individual’s stories within a unifying, more general, plotline”. However, Brown and Addington-Hall’s recommendations for managing each narrative type may be useful for healthcare professionals:

1. Sustaining narratives - Offers a window of opportunity to enhance a positive perspective with their patient, supporting them to live their life with as much normality as possible.
2. Preserving narratives - Alternative medicines considered.
3. Enduring narratives - Offers opportunities to embrace the person socially, to listen to their sadness, to plan time to be with them, and to support their sense of self and worth.
4. Fracturing narratives - Raises the value of listening and understanding their distress (p.206).

Brown and Addington-Hall (2008) discussed the study’s limitations as not examining the differences in the four presentations of MND, nor did they examine the differences in stage of symptom presentation, and this merits further study. A health care professional would need this background information to understand further why the story is being told in this way. For example, a person diagnosed with PBP MND may already have a loss of speech, so their story may be told through the use of light writer or other media; they may have only months to live and not years, hence the “fracturing narrative”. In contrast, a person diagnosed with ALS MND may not have a loss of speech. They may be experiencing loss of movement in their upper/lower body. Therefore, they may have years to live, hence the “sustaining narrative”. The findings of loss, breakdown of self, and fear of the future are important intrinsic aspects of existence. Similarly, other studies have also found people living with MND do have existential concerns (Bolmsjö, 2001), and carers of people living with MND have observed existential suffering (O’Toole, 2011). These studies are reviewed again in a later section of this thesis.

2.3.6 SUMMARY

This section has reviewed the available literature on living with MND. The current data in the U.K. has shown that receiving a diagnosis of motor neurone disease (MND) represents an “existential shock” (Brown, 2003), a “biographical abruption” to a previously planned life (Locock et al., 2009), and a ‘fracturing narrative’ concerned with loss and fear of the future (Brown and Addington-Hall, 2008). All of which point to people living with existential concerns. Brown and Addington-Hall (2008) also have three other narrative types: ‘sustaining’ and ‘preserving’, which represent people coping with their difficult situation, and ‘enduring’, which suggests quiet suffering facing death. The next part of the thesis will review the current available evidence on receiving health care.

2.4 DISCOURSE ON RECEIVING HEALTH CARE

2.4.1 INTRODUCTION

The next section of the thesis will review the current available evidence of people living with MND and their carers on service use and needs; whether services are meeting needs; perspectives on a multidisciplinary team approach; service users’ views, experiences and perspectives on receiving health care.

2.4.2 SERVICE USE AND NEEDS

van Teijlingen, Friend and Kamal. (2001) were interested in the service use and needs of people with MND and their carers. Using a mixed methodological approach, they interviewed 153 patients and included the following areas of use: medical, social and voluntary services; (expected) use of specialist equipment; satisfaction with services provided; and standard demographic data. In addition, the assessment of the respondents’ level of impairment used the standardised assessment measure, namely the Amyotrophic Lateral Sclerosis Severity Scale (ALSSS). Using SPSS-PC to analyse their data, they discovered:

- 60% of the cases were severely disabled;
- 19% of the cases reported health services did not meet their needs;
- 24% of the cases reported social services did not meet their needs;
- 80% of the cases had an identified carer.

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They concluded that services need to be proactive rather than reactive, and should plan ahead for people's changing needs. van Teijlingen et al. classify needs as mobility aids, chairs, wheelchairs, pressure care, respiration, moving/handling, and communication. This study was carried out in Scotland, where health care professionals follow different Government policies and procedures to the U.K.

In a study to investigate whether available services met the needs of patients with MND and their carers, Brown, Lattimer and Tudball (2006) carried out their research using a mixed methodological approach. Using a postal survey of health and social care commissioners in three counties of Southern England. The questionnaire had three parts: access to services, assessment and referrals, and actual service provision. In addition, they carried out semi-structured interviews with eleven patients and nine carers. The interview included three main questions: the range of health and social care services currently received; the main strengths of the services received; and three changes in services the patients and carers would like to see, and why. The study identified the patients' and carers' priorities for service provision in MND. These included increased knowledge of MND, a key worker for every patient, availability of specialist equipment, faster response, better coordination of services, MND-focused care, availability of respite and hospice care, and the chance to give feedback (p.251). This study by Brown et al. (2006) highlights that the participant focus is on the practical aspects of health care.

With the introduction of the MNDA Care Centres across the U.K., O'Brien, Whitehead, Jack and Mitchell's (2011) study focused on the patients' and family caregivers' perspectives of a multidisciplinary team approach at the MNDA Care Centres. O'Brien et al. used narrative style interviews with 24 people with MND, 18 current carers and 10 former carers. The study identified advantages including having a single point of access to one service, where experts have specialist knowledge and skills; this saves time and energy. The authors restricted their interviews to those patients who attended the MNDA Care Centres; as such they do not explore the perspectives of those patients who did not attend the MNDA Care Centres, but who are still receiving multidisciplinary service in the community.

Foley, Timonen and Hardiman (2011) undertook a systematic review of empirical data published between: 1988 to 2011. The focus of this study was ALS service users' views,

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experiences and perspectives of health care and services. The qualitative views of services reported by Foley et al. are similar to those made earlier in the literature review sections:

- The primary expectations are the need to be valued by health care professionals and to be acknowledged independently of their disease (Bolmsjö, 2001).
- Patients expressed concerns about inadequate emotional support, and lack of continuity and coordination within the services provided (Brown, 2003).
- Most qualitative research in the UK has focused on expectations of care and receipt of care? (Brown, 2006; Hughes, et al., 2005; O'Brien, et al., 2011).

The above papers reviewed by Foley et al. have also been reviewed separately in this chapter. Similar conclusions have been reached by each of the research studies. Moreover, people with MND need to be acknowledged independently of their disease. Foley et al. conclude that the majority of the research on patient perspectives on health care provision in MND originate outside of the U.K. Foley et al. recommend further research that would focus on the timeliness of services to meet the changing needs of people living with MND.

2.4.3 SUMMARY

This part of the thesis has suggested that the needs of people living with MND are not being met because the care tends to focus on the functional needs of the person living with MND (Brown, 2003; Hughes, et al., 2005; van Teijlingen, 2001). Brown (2003) argues that people need to be acknowledged independently of their disease. However, people may not be acknowledged independently of their disease, because from the time of diagnosis the guidelines recommend that care should focus on the person with MND and their loss of function.

2.5 OVERVIEW OF THE BACKGROUND/LITERATURE ON MND

In this chapter, an overview of the current available literature shows that MND is a life-threatening neurodegenerative disease. People may receive a diagnosis of ALS-type MND, or PBP-type MND. Depending on the type of MND diagnosed, people may have months to live or years (MNDA, 2013). People receiving a diagnosis of MND experience it as an “existential shock” (Brown, 2003) and a “biographical abruption” of life (Locock, et al., 2009), and they

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talk about loss and fear of the future (Brown and Addington-Hall, 2008). These studies highlight that people living with MND have existential concerns. The focus of care in the U.K. is on the person living with MND and their loss of function. Only if a person is experiencing loss of speech, loss of respiratory function, or nearing the end of their life are they referred into the palliative care services (MNDA, 2013). Oliver (2002) calls for palliative care for people diagnosed with MND, because palliative care focuses on the physical, psychological, social and spiritual aspects of MND. The current available evidence suggests that the needs of people living with MND are not always effectively met (Brown, 2003; Hughes, et al., 2005; van Teijlingen, 2001). One reason may be because the care people receive is based on objectified care pathways, focused on the person and their disease. It does not acknowledge the patient in a wider temporal frame, and beyond their illness context. The next chapter of this thesis introduces a hermeneutic phenomenological perspective on the meaning of being (existence), which brings forward both the ontic and ontological aspects of human existence.

CHAPTER 3 - THE MEANING OF BEING (EXISTENCE)

“We are rooted in a past and thrust into a future. We inherit a past tradition that we share with others, and we pursue future possibilities that define us as individuals. As we do so, the world opens up for us, and beings get understood; it makes a difference to us that there is something rather than nothing. Our historicity, then, does not cut us off from reality – to the contrary, it opens us up to the meaning of being” (Heidegger in Polt, 1999, p.5).

3.1 INTRODUCTION

Martin Heidegger (1889-1976) was a German philosopher in the field of existential phenomenology and philosophical hermeneutics. In this section, his philosophical perspective on the meaning of being (existence) is presented, and is taken from the translated understandings of Heidegger’s work (Ashworth, 2006; Cohn, 1997; Finlay, 2011; Irving, 1997; Koch, 1995; Moran, 2000, Polt, 1999). Heidegger’s phenomenology evolved through his study of existential philosophy (Yagi, 2011) and as a challenge to the Cartesian assumptions (Polt, 1999). This chapter will explore how the understanding of the meaning of being (existence) evolved, and frame this research in that context. The reason for introducing this philosophical stance to the research is that the existing literature has shown that individuality and sociality are lost in the care of people living with MND, a life-threatening illness.

3.1.1 DESCARTES’S PHILOSOPHY

René Descartes (1596-1650) was a French philosopher and mathematician whose philosophy represented the model of the mind and the mind-body split known as Cartesian duality; this idea offers a mechanistic view of a person (Koch, 1995). Heidegger was opposed to the Cartesian beliefs of the mind-body split, his wish being to dissolve the dichotomy of subjective/objective and internal/external (Polt, 1999). He understood that the process of human existence does not take place “inside” the human body; on the contrary, it occurs when

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the human body interacts with other beings around it and in such a way that those beings reveal themselves in their depth of meaning (Polt, 1999).

3.1.2 HUSSERL'S PHENOMENOLOGY

Edmund Husserl (1859-1938) was a German philosopher who established the school of phenomenology. Husserl's method of approaching phenomenology was based on "intentionality" and "reduction." Intentionality refers to the interaction between the consciousness mind and objects (Koch, 1995). Firstly, to explore in more detail the notion of intentionality and Heidegger's thought: Heidegger understood that mental orientation and the object of awareness are both aspects of experience, rather than a relation between them; he also emphasised that the meaning of the object of awareness was embedded in the lived context (Ashworth, 2006). Secondly, to explore in more detail the notion of reduction and Heidegger's thought: reduction is a move to bracketing "reality" (often referred to as "epoch") as a means of dealing entirely with descriptive psychology, and the elimination of any preconceived ideas (Koch, 1995). This process involves: 1. setting aside the question of whether what is experienced is real or not; 2. attending to the experience as it is given to consciousness; 3. setting aside the experiences of the researcher; 4. and setting aside the researchers accumulated knowledge of scholarship (Ashworth, 2006). Heidegger rejected Husserl's process of "reduction". Finlay (2011) throws light on this rejection:

Heidegger described his approach to the study of human existence as 'hermeneutical' meaning that interpretive steps are taken between the implicit pre-understandings and evolving current understandings; between the interpreter and that which is interpreted; between understanding the whole and its parts" (Finlay, 2011, p.52).

3.1.3 HEIDEGGER'S HERMENEUTIC PHENOMENOLOGY

"Hermeneutics is the revelatory aspect of 'phenomenological seeing' whereby existential structures and then being itself came into view" (Heidegger in Crotty, 1998, p.96).

Cohn (1997) states that Heidegger's existential phenomenological approach is both ontic and ontological. The ontic approach is concerned with the particular ways in which a person is in the world. The particular ways include being-in-the-world, being-with-others, spatiality and temporality. The ontological approach is concerned with the intrinsic features of being which

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are “given” and inescapable. The “givens” that are inescapable include thrownness, mortality, embodiment and mood. According to Cohn (1997), Heidegger understood that all human beings have a basic understanding of their own ontological aspects of being; however, for most of the time they choose to hide behind their ontic concerns, and in doing so the challenges of existence may be experienced as the demands and pressures of personal life. The aspects of existence most commonly used are further described by Cohn (1997) (see Table 6 below):

TABLE 6 ONTIC/ONTOLOGICAL ASPECTS OF EXISTENCE (TAKEN FROM COHN, 1997)

Ontic aspects of being	Definition
Being-in-the-world	Describes our involvement with all that there is; as such, we do enter the world from outside but are always part of it; this involvement Heidegger terms “care”.
Being-with-others	Is a primary state of one’s being: we cannot choose to be-in-the-world without other people. But we can choose how to respond to this relatedness, which is also termed “inter-subjectivity”. We have a choice to concern ourselves with it or turn our back on it.
Space	If existence is being-in-the-world, it is “spatial” – that is, part of a wider context to which it is related. But the space between different parts of this context is not measurable in feet and yards but is experienced differently at different times; what is close today can be distant tomorrow.
Time	We are “temporal”, as we are our history, moving from birth to death. The past is carried along by a present that is already anticipating the future (pp. 13-15).
Ontological aspects of being	Definition
Thrownness	Refers to the limits of our control over existence. As such, life is conditioned in many ways: from birth onwards we find ourselves in situations not of our choosing.
Mortality	A person projects their future, because of the awareness of the inevitability of death. It is our ultimate limitation that we can choose to deny or accept death as an intrinsic aspect of living.
Embodiment	All being is physical and non-physical (Cohn, 1997). The non-physical being relates to psychological, social and spiritual dimensions (van Deurzen and Baker, 2005). Heidegger focused on embodiment as ways of being (physical, psychological, social and spiritual) (Inwood, 1997).
Mood (attunement)	Describes the affective aspect of the experience of Being-in-the-world. It is important not to see this as a simple one-way reaction to the world – mood does not only respond to what it meets, it also discloses it. For example anxiety is not just a response to the fact of finding yourself ‘thrown’ into the world – it is through anxiety that you become aware of this thrownness. (pp. 13-15).

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Cohn (1997) summarises the different aspects of existence in the following statement:

“human existence is always in the world, in space, in time, in the body, emotionally ‘attuned,’ intersubjective and limited by death” (p.13). The above aspects of existence applied to the participants’ stories help to understand (interpret) each participant in their lifeworld.

Heidegger holds that to understand a person in their lifeworld you must first turn to their existence and everydayness (Polt, 1999).

3.1.4 EXISTENCE AND EVERYDAYNESS

“The essence of Dasein lies in its existence” (Heidegger, 1962, in Polt, 1999, p.44).

Heidegger understands that it is only through reflection on our being-in-the-world that we have a grasp on our own self (Ashworth, 2006). Polt (1999, p.44) has interpreted Heidegger’s existence and everydayness, and he suggests asking the question: “Who are you”? In response to this question, I am now going to reflect on my own existence and everydayness, using Heidegger’s analysis: I am a white British, Christian occupational therapy researcher, a wife, mother of three, and a grandmother. Being British, a mother, and other dimensions of my identity are not just facts given here and now. They are part of my past, and also part of my future, because they open up possible ways for me to be in the world. I am able to act, think and feel like a mother, a Christian and an occupational therapy researcher. Whenever I realise one of these possibilities, I am choosing to be someone, I am interpreting who I am. The question of who I am, is always an issue for me, as I will always be assigned to being someone, whether I like it or not. I may choose to acknowledge this responsibility and accept my existence as my own to take over, or I may exist ‘inauthentically’, avoiding owning up to the task of being. Either way, the task is mine for as long as I shall live. Polt (1999, p.99) offers an interpretation of what happens when existence, everydayness and temporality are disrupted (see table 7 below), the concepts in this table are then applied to my own life situation.

TABLE 7 EXISTENCE, EVERYDAYNESS AND TEMPORALITY (TAKEN FROM POLT, 1999)

	Past	Present	Future
Inauthentic	Forgetting	Making-present	Awaiting
Authentic	Repetition	Moment of vision	Anticipation

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As I go about my being-in-the-world as an occupational therapy researcher, my attention is consumed with performing this familiar role. As Heidegger puts it, I am what I do, I define myself as an occupational therapist, doing research. I am wrapped up in this role, and I am concerned with whether I will succeed in obtaining my Master of Philosophy. My being-in-the-world is inauthentic because I have forgotten my past, I have fallen into the present environment, making present the things I am dealing with, and awaiting the result of my research. Should I suddenly be faced with something untoward happening to me, as is the case with the participants involved in this study? I may anticipate my mortality because I experience my possibilities as limited. I am now capable of authentic existence by repeating my choices, taking up my previous life, reinterpreting it and reaffirming it (Polt, 1999, p.99). Repeating choices, and taking up their previous life may be difficult for people living with MND, a degenerating life-threatening condition. Though reinterpreting life and reaffirming authentic existence may be achievable.

The work of Frankl (1959 in Frankl 2004) takes up this point, as he emphasised how people “search for meaning” in extreme conditions. Viktor Frankl (1905-1997), an Austrian neurologist and psychiatrist, provides a profound account of man’s search for meaning, first published in his 1959 book entitled *From Death-Camp to Existentialism*. Like most Austrian Jews he was taken from his home along with his family to one of the many concentration and extermination camps in Auschwitz, Poland. People were hoarded onto the trains not knowing their fate; they were stripped of most of their possessions and dignity; the Capo (prisoners with special privileges) waited to meet the prisoners. Frankl found meaning through his suffering by reflecting back on his past. The past holds our assets as Weisskopf-Joelson (1984, in Frankl, 2004) states: “Realities in the past, the potentialities they have actualized, and the meanings they have fulfilled, the values they have realised, and nothing and nobody can ever remove these assets from the past” (p.151).

Polt (1999, pp.99-100) emphasises Heidegger’s thought on existence, everydayness and anxiety: “when man experiences anxiety, he gets in touch with the deeper modes of the ecstasies of temporality”. However, in extreme conditions this may prove difficult. Inwood (1997, p.58) extends Heidegger’s thought to the meaning of existence in extreme depression

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or anxiety, stating: “the closest we come in our waking state to lacking care, we find it hard to will or to wish for anything, even for release from our condition”. Cohn (1997) further emphasises the meaning of existence when facing death as a certainty by arguing:

The certainty of death is perhaps the most unacceptable dimension of existence. What is intolerable is not only the constant threat of our mortality but also the acceptance of our finiteness. We do not wish to give up our illusions of omnipotence or our hope of immortality. We may extend these attitudes to any kind of separation or loss. To live as if we were immortal, to ignore [the] separation, to refuse to mourn our losses, are all poignant instances of living inauthentically (Cohn, 1997 p.126).

By contrast, authentic human life can be found in a person who constantly projects their life onto the horizon of their death, termed by Heidegger as being-towards-death (Critchley, 2009).

3.1.5 SUMMARY

This part of the chapter has unpacked, with the help of other authors, Heidegger’s central ideas of existential, hermeneutic phenomenology. In the process of unpacking Heidegger’s existential, hermeneutic phenomenology, other phenomenological approaches such as Husserl’s descriptive phenomenology were rejected as not being appropriate for this study. Other authors/researchers have understood Husserl’s approach to be cognitive (Moran, 2000), or mechanistic (Koch, 1995). The fundamental difference between the two phenomenological approaches is understood as follows: those using Husserl’s epistemological method are interested in a theory of truth, as judgement, while in contrast, those using Heidegger’s ontological thoughts are interested in an experience of truth, as revelation (Moran, 2000). The participants involved in this study have been living with MND, a life-threatening illness, and experiencing motor neurons progressively degenerating for some time, thus impacting on all aspects of their existence (past, present and future). It is acknowledged that each person will respond differently to the “givens” of being diagnosed with MND. This study aims to give the participants the opportunity to reveal their ontic and ontological aspects of existence. The next part of this thesis will explore the available evidence on discourse on existential concerns and existential suffering in MND.

3.2 DISCOURSE ON EXISTENTIAL CONCERNS AND EXISTENTIAL SUFFERING

3.2.1 INTRODUCTION

This section of the thesis will introduce the studies that have identified existential concerns and suffering for people living with MND. Existential concerns and existential suffering may relate to aspects of existence. Aspects of existence relate to life and death, embodiment and identity, choice and meaningfulness, belonging and needs, time and space, freedom and oppression (Finlay, 2011). This section of the thesis will show how existential concerns and suffering seem to differ across the world. For example, existential concerns have been brought to the forefront for those people living with MND in Sweden (Bolmsjö, 2001), and in the U.K. (Brown, 2003). Existential suffering has also been observed by those caring for people living with MND in Ireland (O'Toole, 2011). The Court of Protection in the U.K. made a landmark decision for one man living with MND who was existentially suffering (Doughty, 2012). In Japan existential suffering is a major concern for people living with terminal cancer (Murata and Morita, 2006). Boston, Bruce and Schreiber (2011) argue that the treatment of existential suffering is limited. These individual studies and cases will be reviewed in more detail.

Health care professionals often undertake research because of experiential concerns (Finlay, 2011). Brown (2003), a senior nurse on a neurological ward, experienced differing care conditions for people living with MND. She describes her research as an “application of the principles of phenomenology and hermeneutics [that] is congruent with seeking a greater understanding of meanings of experience and phenomenon, inclusive of care”. Brown’s study explored the meaning of being-in-the-world of MND and care values. Her participants included patients, lay and professional carers. The researcher asked people living with MND: “What is it like to have MND?” and asked those caring for people with MND (lay carer/health care professional): “What is it like to care for a person with MND?” (p.209). Patient experiences of MND included eight themes: existential shock, the value of creating meaning, temporal realizations, struggling with increasing loss of control, changing relationships, dynamic normality, strength and limitations of receiving care, and learning to accept care. Professional carer stance on providing health care included seven themes:

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strengths of professional role, ideals of care, role limitations, quality of inter-professional co-operation, situated friendship, the critical nature of time, and learning through the experience of caring. Brown (2003) highlights the professional carer stance is functional in contrast to patients' needs are holistic, the reason given for this variance is care focused on reducing suffering. Brown stresses: "the need for professionals and carers to interact with people with MND as 'being human in extremis' cannot be overemphasized, and keeping the focus on the person, rather than the disease appears so simple, yet so challenging" (p.215). Brown's (2003) used Heidegger's hermeneutic phenomenology to frame her study, though this study focus was on care values.

3.2.2 EXISTENTIAL CONCERNS IN MND

Before a person receives a diagnosis of MND they may have fears of tests, diagnosis, disease progression, death and dying (Boraiso, et al., 1998). Irrespective of the disease or social background of the sufferer, existential concerns are important (LeMay and Wilson, 2008). Using a hermeneutic phenomenological perspective, Bolmsjö (2001) explored how people living with MND communicate their existential concerns. The participants took part in semi-structured interviews focusing on the experience of their present situation and their feelings about the future. The findings included fear of not being able to control and affect their current and future lives, the current situation, and the stress of the dying process which creates anxiety and thoughts of suicide and euthanasia. Bolmsjö states: "the latter two may be some of the taboos within the care of patients with ALS" (p.503). Bolmsjö's study has identified important ontological aspects of Being, related to thrownness (limits of control over existence) and mortality (a person projects their future because of the awareness of death).

There is a definite contradiction in the evidence of the appropriate time to discuss needs, priorities, preferences and end-of-life care decisions for people living with MND. Preston, Fineberg, Callagher, and Mitchell (2012) argue for early discussion of needs, priorities and preferences with the patient and their family, which has to be a primary concern because a person is at risk of losing their ability to communicate by any means; their recommendations are for all people diagnosed with MND, regardless of type of MND. In contrast, Munroe, Sirdofsky, Kuru and Anderson (2007) argue that patients diagnosed with ALS MND learn

that their life expectancy is years rather than months, and therefore professionals may not discuss end-of-life care decisions so early in the illness trajectory.

Stein and Fineberg (2013) have reviewed the different cultural views in the U.S. and U.K. on setting up Advance Care Plans (ACPs). In the U.S. people have been setting up ACPs regardless of their health status. In the U.K. ACPs tend to be brought to a person's attention when a person becomes a patient with a life-limiting illness. The implementation of the Mental Capacity Act (MCA) (2005) in the U.K. brought about changes to the laws for people at risk of losing their mental capacity at their end-of-life (DCA, 2007a, DCA, 2007b, Harris and Fineberg, 2011). People with life-limiting illnesses are at risk of losing their mental capacity because of end-of-life medication (NCPC, 2008); therefore, making the MCA (2005) highly applicable to people living with MND. Sakellariou et al. (2012) have a contrasting view, and argue that in people living with MND mental capacity usually remains intact, adding that they are aware of the progressive nature of MND. The process of assessing mental capacity to make a decision is challenging for palliative care professionals, and the process of considering their patients' best interests may not directly reflect the specific guidance of the MCA (Harris and Fineberg, 2011). This raises concerns if health care professionals are not enabling people to discuss and document end-of-life concerns, needs, priorities and preferences whilst a person can still communicate.

3.2.3 COURTS' RECOGNITION OF DECISIONS

“A landmark decision is the first in which a judge at the Court of Protection, the division of the High Court which rules on life-and-death medical decisions, has approved a contested living will which calls for the death of a medical patient” (Doughty, 2012).

This case was brought to court because a living will (advance directive) was given legal force in the U.K. by the introduction of the Mental Capacity Act (2005) (DCA, 2007a). Ray, Brown and Street (2012) acknowledged that people living with MND should be cared for at home until close to death, and, as Bolmsjö, they understood that the discussion of dying for those involved in their studies remained a taboo. Ray, Brown and Street acknowledged the importance of discussing life and death concerns for people living with MND. Ray et al. show how the dying process can be improved by providing knowledge on the progressive nature of MND and the dying process, preparing and planning for death, and preserving

dignity for the person. They conclude that, despite limited survival, discussions about dying are difficult, and are linked to hope. Similarly, in her unpublished thesis O'Toole (2011) reports on the narratives of those who have cared for their partners living with MND over months and years. O'Toole found a common theme from the narratives was to shield their partners from discussing MND and dying, she defined this as "closed awareness". The idea of maintaining hope has been linked to advanced care planning (Davison and Simpson, 2006). Davison and Simpson state:

Current disclosure practices are ethically and psychologically inadequate in that they do not meet the needs of our patients. In addition to this, although the study was carried out in the context of end stage renal disease, these data are probably relevant to all clinicians who treat people with advanced disease (2006, p.4).

This present study may uncover the current disclosure practices for the participants. The next section of this thesis examines existential suffering in terminal cancer, and considers how the findings may relate to people living with MND.

3.2.4 EXISTENTIAL SUFFERING IN TERMINAL CANCER

Researchers in Japan have designed a conceptual framework for understanding the meaning of psycho-existential suffering when diagnosed with terminal cancer (Murata and Morita, 2006). Murata and Morita's conceptual framework is based on Heidegger's (1962) existential philosophy and the understanding that meaning is the *existentiale* of Dasein. Murata and Morita state:

Meaning is thus a basic concept that makes the Being of oneself possible, and people ultimately feel meaningless when they lose the basic elements supporting them, namely, relationships, autonomy, or temporality (Murata and Morita, 2006, p.282).

Murata and Morita's conceptualisation of psycho-existential suffering aims to support researchers to understand the meaning of existence when people experience loss of relationships, autonomy or temporality (see Appendix H). This table highlights how loss of relationships, autonomy and temporality are conceptualised in terms of the person having a past, present and future. For example, past relationships, present need to remain in control and experience a continuity of self, and a future with anxieties and the hope to live to the end with a quality of life. This framework applies to anyone living with a life-threatening illness.

3.2.5 EXISTENTIAL SUFFERING IN MND

In MND, existential suffering was defined as a loss of speech and movement by those caring for people living with the condition (O'Toole, 2011). Loss of speech and movement may also have a profound impact on a person's relationships, autonomy, and temporality. Locock et al. (2009) defined the impact of MND as a "biographical abruption" to a life already over. Locock listened to the story of one man who cried for six months and moved into the spare bedroom, his relationship with his wife being over. They also recounted stories of people experiencing a loss of identity as a parent or a work colleague, and stories of people experiencing loss of a planned future: retirement and seeing their children grow up. Loss of hope left one man wanting to go off into the mountains to end his life. Though Locock et al. do not define their findings in terms of existential suffering, they do correlate with Murata and Morita's conceptual ideas (2006). Boston et al's comprehensive literature review (2011) revealed that existential suffering at the end of life is recognized as a debilitating condition, and that little is understood about how to treat it.

3.2.6 BURDEN TO OTHERS AT END OF LIFE

Fear of becoming a burden is a concern for people nearing their end of life (McPherson, Wilson and Murray, 2007). McPherson et al. carried out a systematic review focusing on the end of life and self-perceived burden (SPB). McPherson et al. acknowledge that SPB is at the core of existential distress, and impacts on end-of-life decisions, including the desire to end one's own life. Johnson, Sulmasy and Nolan (2007) argue that health care professionals should assess how people diagnosed with a terminal illness are managing the transition from being an independent person to becoming dependent on others. SPB may have relevance for people living with MND, and, therefore, needs to be explored early into a person's disease trajectory, well before a person loses their ability to communicate. This, as Murata and Morita have argued, may help reduce existential suffering. Heidegger's view on anxiety and being-towards-death: "death can only be authentically experienced by us if we become totally secure with our first-person experience of dying – our genuine anticipation of death" (Moran, 2000, p.240). What Heidegger is emphasising is the need for people to remain in control of their future, even when facing death.

3.2.7 SUMMARY

The current available literature suggests is that existential concerns and existential suffering are central in health care in Sweden and Japan, and have been recently brought to the forefront the U.K., Ireland and Australia. The current available evidence suggests that existential suffering and existential concerns may begin before the end of life for people living with MND, and may even begin before people receive a diagnosis of MND. Because people may have lost relationships, autonomy and temporality early into their disease trajectory, they may have a fear of life and death. How are health care professionals in the U.K. treating people for such loss?

3.3 OVERVIEW OF THE BACKGROUND/LITERATURE ON THE MEANING OF BEING (EXISTENCE)

This study has proposed hermeneutic phenomenology to understand the meaning of being (existence) through time (Heidegger, 1929/62). It is understood that each person will have their own unique experience of MND and that it may be possible to identify generalities. Existential concerns have been the main focus of research for people living with MND receiving palliative care in Sweden (Bolmsjö, 2001), and, more recently, the focus of secondary analysis of two studies carried out in the U.K. (Brown, 2003) and Australia (Ray and Street, 2007). Existential suffering has also been observed by those caring for people living with MND in Ireland (O'Toole, 2011). It is anticipated that the participants involved in this study may also have existential concerns and existential suffering as they live through the illness trajectory of MND. There is a gap in the literature dealing with existential concerns and existential suffering in people living with MND in the U.K. and how health care professionals are treating existential concerns and existential suffering.

3.4 PURPOSE AND AIM OF THE STUDY

The purpose of this study is to gain an understanding of life with MND, receiving health care and the impact on self and identity, in order to contribute to caring policy and practice. The aim is to answer the research question: "What does it mean to be a person living through the illness trajectory of MND?" and to study the phenomenon of existence when given a

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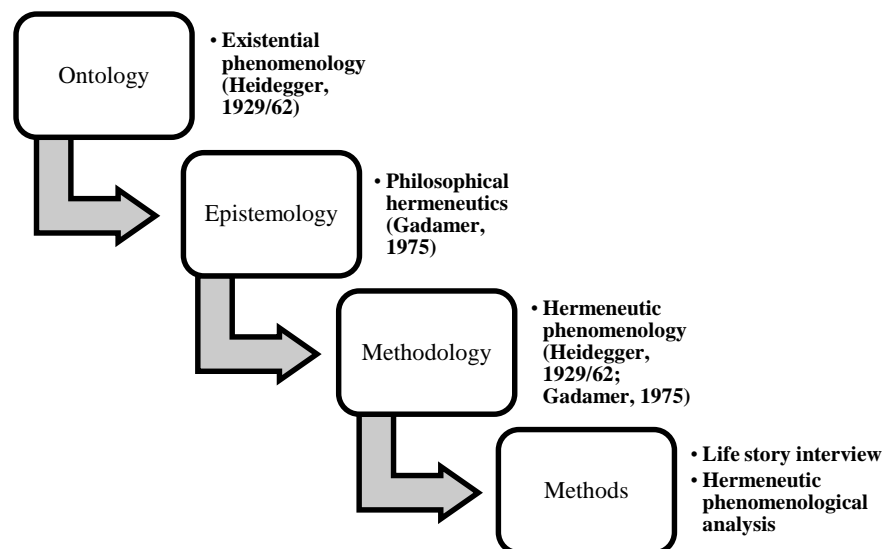
diagnosis of MND in the context of receiving health care through time. The next chapter argues that Heidegger's existential phenomenology and Gadamer's philosophical hermeneutics are the appropriate methodologies for this study.

CHAPTER - 4 ONTOLOGY, EPISTEMOLOGY, AND METHODOLOGY

4.1 INTRODUCTION

Hermeneutic phenomenology sits within an interpretive paradigm (Sarantakos, 1998). It offers particular perspectives on ontology, for example, what kind of being is a human being? What is the nature of reality? on epistemology, for example, what is the relationship between the inquirer and the known? And on methodology, for example, how do we know the world, or gain knowledge of it? (Guba, 1990, p.18). Chapter 3 described the ontic/ontological approach used to frame this study. This chapter will further discuss how the questions posed by Guba (1990) have been applied to this study as an interpretive paradigm (see Figure 1 below):

FIGURE 1 INTERPRETIVE PARADIGM



4.2 ONTOLOGY

4.2.1 WHAT IS THE NATURE OF REALITY?

Being diagnosed with a life-threatening disease like MND is devastating; at the time of diagnosis people have already experienced what it means to be losing upper/lower motor neurones and the impact this has on their movement and speech. Loss of movement and speech may have a profound impact on their individual ways of being-in-the-world, being-with-others, spatiality and temporality. To study such a complex phenomenon using a quantitative positivistic line of enquiry would not provide the lifeworld experiences this study seeks to understand. The argument here is that the meaning of existence cannot be interpreted through a positivistic quantitative perspective. However, this view is not rejected because a positivistic quantitative perspective does mean researchers can meet larger communities. On the other hand, qualitative research based on hermeneutic phenomenology allows for a small sample of people to be explored in-depth. In the exploration of the current available literature, the daily lived experiences of MND by the participants have not been understood in the context of those people's life situation and projects.

4.3 EPISTEMOLOGY

4.3.1 WHAT IS THE RELATIONSHIP BETWEEN THE ENQUIRER AND THE KNOWN?

Gadamer (1900-2002), inspired by the work of Heidegger, was to advance philosophical hermeneutics (Schwandt, 2000). Gadamer's advances included focusing on the process of the 'hermeneutic circle'. Gadamer introduced the concept of 'horizon' to describe a person's location in their history and culture, which offers possibilities and limitations of understanding. In order to learn something new or to see the otherness of something, one must have an open mind, to raise our gaze beyond our normal horizons, to allow a dialogue between past and present, a 'fusion of horizons' (Finlay, 2011). Gadamer introduced the concept of presuppositions, defined as pre-understandings, prejudices, and beliefs. Gadamer, like Heidegger, understood that presuppositions cannot be "bracketed" as though they do not exist. Instead, Gadamer recommends engagement and with one's own presuppositions in order to understand the meaning of ourselves and others. Schwandt (2000) states that the researcher adopting this position for their study is taking a non-objectivist view of the

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meaning. I have examined my background experiences of observing my mother living with MND while receiving health care, and how I experienced a disquiet when observing other health care professionals struggling to manage the impact of MND on my mother. These experiences raised a number of unanswered questions, and were brought to the forefront ahead of carrying out the participant interviews. This process helped me to come to terms with and consider what experiences remained important to me as a health care professional. The participants understood that I had both a professional and personal understanding of how PBP MND affects people in different ways. This shared understanding meant that as a researcher I enter the hermeneutic circle with openness (Gadamer, 1975; Geanellos, 1998). Atkinson (1998) also acknowledges that shared understanding of the topic can naturally lead the participant to reveal more than he or she would to someone else.

In his response to those researchers who take a more positivist line of enquiry, and who may question experiences of researchers close to MND, Gadamer states:

Our situating the other's meaning in relation to the whole of our own meanings or ourselves in relation to it. This kind of sensitivity involves neither "neutrality" with respect to content nor the extinction of one's self, but the foregrounding and appropriation of one's own fore meanings and prejudices. The important thing is to be aware of one's own bias, so that the text can present itself in all its otherness and thus assert its own truth against one's own fore-meanings (Gadamer, 1975, pp.268–269).

This hermeneutic approach contributes to the creation of reality in the following way:

1. Bringing presuppositions to consciousness before data collection and during interpretation;
2. The choice of data collection method;
3. Whole stories transcribed - so that others could analyse them;
4. Themes raised in the story taken back to participant for validation – fusion of horizons;
5. During the stages of interpretation the focus has been to remain as present as possible to the existential phenomenon (via the participant story);
6. Use of a philosophical framework to analyse the text that focuses on the participant's meaning of existence (lifeworld) and not the researcher's;
7. Use of participant stories (excerpts) to bring resonance to the findings.

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For a further detailed evaluation of the process of reflexivity refer to Chapter 8- Reflexivity of this thesis.

4.4 METHODOLOGY

I was originally going to use biographic narrative interpretive method (BNIM) and then I adjusted my approach. I understood from the literature that the BNIM of data collection draws on hermeneutic phenomenology (Finlay and Ballinger, 2006). It does this because the data collection method enables people to explore their past experiences in the present horizon, and in the horizon of future expectations (Breckner, 1998). The BNIM analysis is informed by a number of theories, such as: Social constructionism (Berger and Luckman, 1966); Grounded theory (Glaser and Strauss, 1968); and Linguistic analysis (Labov, 1997) (Wengraf, 2001). One of the processes of analysis involves a panel of people with different theoretical perspectives to generate hypothesis. The researcher presents the panel with text segments of lived life events and actions, described as objective data about a person's life, life events as they happened; since lived life happens over time, the data is then ordered into a chronological order. The panel then offer a hypothesis, followed by a counter-hypothesis and a tangential-hypothesis of each text segment. Types of questions asked of the text include: a. how could the event be experienced in relation to the context of age, personal development, family, generation, and milieu? Or b. how could the sequence of events so far shape the lived life – orientations, turning-points, meanings? c. What would I expect to occur next or later in the sequence of the lived life? The next text segment either confirms the hypothesis generation or refutes it. And so the process goes on and is repeated for the whole story (lived life) (Wengraf, 2001).

These are some of the problems perceived with the BNIM analysis. Hermeneutic phenomenologists acknowledge the participants as self-interpreting beings with a unique past life, present experiences and a projected future. It is their meaning of existence that this study aims to understand and interpret. Hermeneutic phenomenologists acknowledge that they bring to the study their own presuppositions (pre-understandings, beliefs and prejudices) to the "hermeneutic circle". It would be difficult to include people on the panel and to ask them to bring their presuppositions to consciousness before embarking on interpreting the data. The BNIM method of analysis is more aligned to studies aimed at understanding more

generalised worlds, such as the experiences of individuals in Europe whose lives have been affected by different forms of “social exclusion” (Chamberlayne, Rustin and Wengraf, 2002). The intention is not to use an eclectic approach for this study, but to pull the threads of hermeneutic phenomenology (Heidegger, 1962; Gadamer, 1975) through the methodology and design. A critical decision was reached early into the second year of this project, and before starting the data collection, to reject Wengraf’s method of analysis. Similarly, other researchers in the field of MND have also rejected the BNIM of analysis, in favour of hermeneutic analysis (Brown, 2003) and form and content analysis (Brown and Addington-Hall, 2008).

4.4.1 HOW WE KNOW THE WORLD, OR GAIN KNOWLEDGE OF IT

The basis of this interpretive inquiry is Heidegger’s existential phenomenology, his understanding of the meaning of existence, and Gadamer’s philosophical hermeneutics to come to the ‘hermeneutic circle’ of understanding (interpreting). Heidegger (1962) emphasised the importance of historicity. Historicity is the way in which “Dasein stretches along between birth and death” (p.425). Polt (1999, p.101) draws on Heidegger’s notion of historicity and temporality by stating: “we might say that because of our historicity, our lives form stories, dramas that unfold from birth to death. Other animals have the sort of life that is studied by biology, but human life also calls for biography”. The way a participant recounts their story represents a self-interpretation of the way their past, their experienced present, and their anticipated future is presently understood by that person (Atkinson, 1998). Asking people to tell their illness stories is a method employed by researchers interested in understanding the lived experience of chronic disease (Gullickson, 1993), coronary artery disease (Robertson-Malt, 1999) and, more specific to this study, the lived experience of motor neurone disease and caring experiences in MND (Brown, 2003). Other authors have used hermeneutic phenomenology with different methodological approaches. The purpose of the following table is to highlight the variety of methodological approaches (see Table 8).

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TABLE 8 HERMENEUTIC PHENOMENOLOGY AS METHODOLOGY

Author	Participants	Philosophy	Methodological approaches	Type of Analysis
Gullickson (1993)	Living with chronic illness	Heidegger	To understand individual lived experiences of chronic illness.	Heideggerian Dasein analysis
Robertson-Malt (1999)	Living with coronary artery disease	Heidegger and Gadamer	To understand the intricacies of everyday lived experience of coronary artery disease.	Hermeneutic phenomenological description and interpretation
Brown (2003)	Living with MND	Heidegger and Gadamer	To gain understanding of caring experiences in MND.	Hermeneutic analysis
Ashworth (2006)	Attending to the lifeworld of a person with Alzheimer's	Husserl, Heidegger, Satre, Merleau-Ponty	To describe the lifeworld of a person living with Alzheimer's.	Lifeworld analysis

Gullickson (1993) states that her approach to the study was to use Heideggerian phenomenology as a philosophical framework. Heidegger's notion of temporality, authentic and inauthentic being "offers a new understanding of the lived experience of chronic illness" (p.1391). Robertson-Malt (1999) states: "Heidegger's notion of being-in-the-world provided an unfoldment of new understandings of the human experience in illness" (p.290). Robertson-Malt used descriptive phenomenology in the initial stages; themes were revisited with participants to ask: "Is this what the experience is really like?" Her interpretation involved searching for essences of experience and uncovered four essences: reminiscing; losing; imprisoning; and questioning. Robertson-Malt's method of descriptive phenomenology and searching for the essences of experience is more aligned to Husserl's phenomenology than Heidegger's. Brown (2003), who applied hermeneutic phenomenology as methodology, states:

Heidegger's (1962) phenomenology offers an interpretive enquiry focus into being in the world of motor neurone disease. Heidegger draws on hermeneutics as his

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approach for questioning and analysing such being and Gadamer (1975) developed Heidegger's hermeneutic stance further through his metaphors of prejudice, the hermeneutic circle, fusion of horizons and historicity (Brown, 2003,p.208).

Brown (2003) recognised the importance of Gadamer's hermeneutics and his idea of presuppositions (history, prejudices and beliefs) in the process of understanding (interpreting) the meaning of another (fusion of horizons). Brown's (2003) purpose is similar to understand being-in-the-world of MND from a user, carer, and professional perspective, though her focus was experiences of care in MND. Ashworth (2006) draws on the work of a number of philosophers (Husserl, Heidegger, Merleau-Ponty and Sartre) to understand the lifeworld of a person with Alzheimer's. Ashworth states: "in any phenomenological research project, we may always ask questions which centre on the interrelated elements of the lifeworld: embodiment, selfhood, spatiality, temporality, sociality, mood-as-atmosphere, project, discourse, freedom and historicity" (p.215). This review has shown how other researchers have used hermeneutic phenomenology to inform their methodologies. The purpose of the research discussed above is to understand the lived experience of chronic and life-threatening illnesses, and similarities can be drawn from the above studies in the following ways:

- Like Brown, Gadamer's presuppositions have been carefully considered before the process of gathering data, and during the stages of interpretation, in order to understand the meaning of another.
- Like Robertson-Malt and Brown, themes were also revisited with the participants to ask: "This is how I have understood your disease journey, is there anything you wish to add or remove?"
- Like Gullickson and Ashworth, understanding (interpreting) involved using Heidegger's phenomenology (aspects of existence/lifeworld dimensions) to find deeper meaning in the participants' stories.

4.5 CONCLUSION

In this chapter, I have argued that Heidegger's (1929/1962) existential phenomenology and Gadamer's (1975) hermeneutics are relevant to understanding (interpreting) the meaning of existence through the illness trajectory of MND. This study has shown how other researchers' methodological approach could be used for this, but to different ends. In the next chapter, the methods designed for this study are described in detail.

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CHAPTER 5 - METHODS

5.1 INTRODUCTION

This next section describes the methods employed in this study: how the study participants were selected and recruited; the ethical considerations, the assessment of capacity, gaining consent, confidentiality and anonymity; method of data collection and analysis, and how rigour has been applied.

5.2 RESEARCH DESIGN

For this study, a life story approach was designed, using one-to-one interviews asking people to tell their story since they first thought something untoward was happening to them. This method of data collection is consistent with Wengraf's (2001) approach. The value of this method is that it encourages people to tell their life stories in their own way, and recognises that life history frames experience, and that meaning is expressed through words and through emotions (Nicholson, Meyer, Flatley, and Holman., 2013). The timeframe between interview one and two was four to six weeks, depending on individual circumstances. This interval was used to interpret the data gathered in interview one. Themes were taken back to the second interview to gain a "fusion of meaning" (Gadamer, 1975). An existential hermeneutic phenomenological method of analysis was developed, inspired by existential phenomenological thought (Heidegger, 1929/1962), philosophical hermeneutics (Gadamer, 1975) and other interpretations of existential hermeneutic phenomenology (Ashworth, 2006, 2006; Cohn, 1997; Crotty, 1998; Finlay, 2003, Fleming, Gaidys and Robb, 2003; Irving, 1997; Polt, 1999).

5.3 GAINING ETHICAL APPROVAL

Permission for the research study was obtained from the NHS Research Ethics Service (NRES), University of Salford Research Governance and Ethics Committee, and the local NHS Research and Development Department prior to the commencement of this study. In addition, adherence to the Code of Ethics and Professional Conduct for Occupational

Therapists (2010) and the Research Ethics guidelines of the College of Occupational Therapists (2003) was maintained throughout the study. A more detailed discussion of the ethical considerations during the conceptualization of this study are discussed later in this chapter (5.8 Ethical considerations).

5.4 STUDY PARTICIPANTS

As the purpose of hermeneutic phenomenology is to interpret the lifeworld experience of people, the sampling method had to select people who would contribute to providing an insight into the phenomenon of existence when given a diagnosis of MND, and in the context of receiving health care. Thus, for the purpose of this study, maximum variation purposive sampling was applied to recruit four participants with an accepted diagnosis of MND (all types) (see Table 9 for inclusion/exclusion criteria). Maximum variation purposive sampling (Wengraf, 2001) was used to ensure that a range of experiences from different stages of disease progression were included in the sample. The participants were recruited from one geographic area in the U.K. According to Patton's (1990) understanding of a maximum variance purposive sampling, the data and analysis will produce high-quality detailed descriptions of each case. This not only provide individual uniqueness, but also shared patterns across the cases, emerging from heterogeneity". This process of sampling is in line with interpretive philosophy because it promotes the inclusion of people with unique and diverse experiences. Other studies have used a small sample size to examine the experiences of chronic disease (Finlay, 2003; Gullickson, 1993; Koch, 1995; Robertson-Malt, 1999) and life-threatening illness (Brown, 2003). A story approach allowed an in-depth exploration of rich material, and the quality of the data provided by four participants is sufficient for the purposes of this study.

TABLE 9 INCLUSION/EXCLUSION CRITERIA

INCLUSION CRITERIA
A person has an accepted diagnosis of MND (all types).
A person is over 18 years of age; there is no upper age limit. Including people under this age limit would provoke further ethical implications.
A person has been receiving a range of care and treatment, which might include two or more professionals.
A person has been receiving care and treatment for longer than a 6-month period.

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EXCLUSION CRITERIA
People were not invited for interview if they have issues regarding mental capacity.
People were not invited for interview if they have issues regarding their own mental health.
People were not invited for interview if they are on the end-of-life care pathway.

5.5 RECRUITMENT

The process of recruitment has been through the consultant and the specialist nurses at a neurological centre. The MND nurse specialists met with the consultant to consider which participants met the study inclusion criteria. The participants were then approached by the MND nurse specialists and provided with the study information sheet. Those participants that showed an initial interest were informed by the MND nurse specialists that the researcher would contact them by telephone in one week. Telephone contact was made with the participants to discuss further the interview processes and whether they still wished to be involved. All of the participants taking part in the study expressed a wish to be involved. Arrangements were made for the preferred place of interview (at the MND Care Centre or in their own home) and at a time suitable for them. The participants were informed about their right to refusal in the information sheet and at the start of the interview(s).

5.5.1 ASSESSMENT OF CAPACITY

People with life-limiting illnesses are vulnerable to losing intellectual capacity at the end of their life, making the Mental Capacity Act (MCA) (2005) highly applicable to palliative care (NCPC, 2008). People involved in this study may be on the rehabilitation care pathway or the palliative care pathway, and therefore the principles of the MCA (2005) apply. The assessment of capacity is decision-specific. The consultant and his team identified the participants in the first instance. They chose the participants because they met the inclusion criteria; those that did not have the mental capacity to consent were excluded from this study. In order for the participants to be included in the study, the MCA principles were considered and applied. The first principle to consider is whether the person is unable to make a decision

for himself, because he is unable to understand, retain, use or weigh relevant information, or is unable to communicate by any means (DCA, 2007).

- The participants were each asked at the start of the interview whether they had read and understood the study information sheet.
- An explanation was given about the processes of data collection and what was required of them in order to complete the processes.
- The participants were asked to recall some of the detail that had just been explained to them and whether they wished to continue with the process of gaining consent.

The assessment of capacity was repeated at the second interview.

5.5.2 GAINING CONSENT

The consent form was read to the participant before he/she provided written or oral consent to take part in the study (see Appendix 2). Three of the participants were unable to sign because of loss of motor function in their upper body; they were asked to give oral consent in the presence of a witness, and this was recorded in writing. Process consent was appropriate for this study, achieved by checking at each stage of data collection whether the participant still wanted to participate in the study. Consent was obtained before starting the second interview (Munhall, 1991, in Addington-Hall, 2002).

5.5.3 DATA PROTECTION

At the start of the interviews, the participants were asked not to use their own names, or the names of health professionals. Where the participants did use identifying names, any reference to the personal names of family members, health care professionals and places, such as NHS hospitals, MNDA Care Centres and local hospices, were removed. The data was anonymised at the point of transcription and then removed from the digital recorder. The voice recordings are stored on individual data files on a personal computer with password protection.

5.6 METHOD OF DATA COLLECTION

Consistent with Wengraf's approach to data collection, a single question was developed aimed at encouraging the participant(s) to tell his/her story of their life since they first felt something untoward was happening to them. It was recommended during the training of the life story method that researchers practise the method with non-participants to gain the skills of listening (Wengraf, 2001). The method of life story was practiced with colleagues asking them to recount an important event in their life that was memorable. The designed question for this study was piloted with the first participant. The process of data collection has involved the following stages:

5.6.1 STAGE 1: INTERVIEW 1

The first interview took place after liaising with each participant in advance, either by telephone or email. The initial communication was to ensure that the participant understood what was involved in the interview process: 1. they are being asked to tell their story; 2. the first interview was in two stages; 3. the story would be interpreted before returning for the second interview. The process involved:

...Can you please tell me the story of your life.... since you first thought there might be something wrong with you? Please begin wherever you like. I will not interrupt you; I will listen to you and only write down some notes. When you finish I will ask you some questions according to my notes.

During the telling of their story I noted the themes in the order they were mentioned, and in the terms used by the participant.

5.6.2 STAGE 2: INTERVIEW 1

The second stage of the first interview involved asking the participant to elaborate on the meaning of their experiences. The process involved:

You said XXXXX
-can you tell me more about the experience?
Or
-do you remember any particular incident or occasion when XXXX?
Or
-can you remember any event involving XXXX?
Or
-can you remember how that came about?

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A decision was made early into the transcription process to provide a detailed transcript of everything spoken about as a prerequisite for interpretation (Mishler, 1986). The participants' stories from interview one were transcribed, summarised and taken back to the participant to read before the second interview. This gave them the option to add/remove any content, and to confirm that I have correctly interpreted their story.

5.6.3 STAGE 3: INTERVIEW 2

The second interview involved asking three further questions in order to gain a deeper understanding of the life being lived:

1. How do you feel your past history impacts on your living with motor neurone disease and receiving health care?
2. How have health professionals made a difference to your quality of life at this present time?
3. How has MND and receiving health care impacted on your being (self and identity)?

5.6.4 TRANSCRIPTION

After all the interviews were completed, and before starting the method of interpretation, I was concerned that I had overlooked the participant intonation of voice, and reasoned that professional transcribers would have detailed rules and instructions for how transcripts should be produced. The change in research protocol has meant going back to the NHS National Research Ethics Service (NRES) to give notice of a substantial amendment to this study. The panel granted the use of a transcription company. What is noted about the professional transcripts is the layout, correct punctuation and identification of intonations in the voices of the participants. The professional transcriptions were easier to analyse line by line, a requirement for the second stage of interpretation (Fleming, et al., 2003).

5.7 METHOD OF HERMENEUTIC ANALYSIS

In respect of a method of interpretation to follow, hermeneutic phenomenology has no actual method to offer researchers (Finlay, 2011). Heidegger introduced aspects of existence to understand (interpret) a person in their lifeworld. Cohn (1997) interpreted Heidegger's ontic and ontological aspects of existence, and those he considered important have been used to interpret the participants in their lifeworld. Gadamer offered the "hermeneutic circle" as a



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process of coming to understand (interpret) the being of something, for example, a text, the phenomenon, or the participant in the research context (Finlay, 2011). Fleming, et al., (2003) interpret Heidegger's and Gadamer's meaning of the hermeneutic circle as gaining understanding of the parts in order to understand the whole. This study has brought forward the two philosophical positions to understand (interpret) the meaning of existence.

5.7.1 STAGE 1: GAINING UNDERSTANDING OF THE STORIES

This study adopted a story approach for gathering data. Heidegger (1927/1962) holds that all being through time is temporal; this involves the past which is carried along by a present that is already anticipating the future. This philosophy has been applied to this study in the following way (refer to Table 10):

TABLE 10 HEIDEGGER'S ASPECTS OF TEMPORALITY APPLIED

Heidegger's aspects of temporality applied		
Experiencing MND from first noticing something untoward was happening	Experiencing MND in the present	Projected future living with MND
PAST 	PRESENT 	FUTURE

Heidegger and Gadamer both understood that gaining an understanding of the whole should be the starting point of interpretation, because the meaning of the whole will influence the understanding of the parts (Atkinson, 1998; Fleming, et al., 2003). The process involved:

1. Iterative listening to the stories and organising them into temporal themes (past, present and future).
2. In the first stage of data collection (interview 1), the participant was asked to tell their story from when they first felt something untoward was happening to them.
 - a. This was naturally told as their experienced past, and was colour-coded in **blue**.
3. In the second stage of data collection (interview 1), the participant was asked to elaborate on the meaning of their experiences.
 - a. Where stories still related to the past, these were also colour-coded in **blue**.
 - b. The stories relating to their experienced present were colour-coded in **pink**.
 - c. The stories relating to their anticipated future were colour-coded in **green**.

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4. In the third stage of data collection (interview 2) the participants were asked three broad questions to enhance their stories.
 - a. The responses to these questions have been put together with the other stories (of **past**, **present** and **future**).
5. Stories that were repetitive or less relevant to the research focus were left out.

5.7.2 STAGE 2: INTERPRETATION OF THE MEANING OF EXISTENCE

Atkinson (1998) recommends having a perspective broader than your own to understand fully a story. Heidegger's (1927/1962) different aspects of existence, as outlined in the background chapter of this thesis, offers a philosophical framework in which to understand what it means to be a person living through the illness trajectory of MND. The aspects of existence (lifeworld dimensions) used for this stage of analysis include: being-in-the-world; being-with-others; temporality; spatiality, thrownness; embodiment; mood; and mortality. Finlay (2011, p.135) offers justification for use of such a framework:

The explicit focus on lifeworld dimensions offers phenomenology a clear pragmatic framework that is well anchored in phenomenological philosophy (and so justified). The framework is one that guides methodology and upon which researchers can hang their understanding.

The process involved:

1. The text was divided into meaning units, condensed, and organized into aspects of existence. The condensed statements are presented to bring closer attention to the metaphors/words/sentences used by the participants to emphasise their lifeworld experiences (Finlay, 2011) (see example in Table 11 below):

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TABLE 11 PHILOSOPHICAL FRAMEWORK ANALYSIS

Philosophical framework analysis		
Meaning Unit	Condensed statement	Aspects of existence
Well my condition started in October, 2009, was the first indication I had a brain thing not right. I lost my tennis racket out of my right hand, while I was playing tennis, and I thought hm.	First indication I had a brain thing not right	Embodiment
Well, in actual fact I would prefer you to have your whole brain and neck scanned, but I didn't get that message until after... because I think I was seeing him on the Thursday, and I was actually having the scan the following Monday.	I would prefer you to have your whole brain and neck scanned	Being-in-the-world-with others
I was diagnosed/ /first week of October, I think, in 2010. So it took a year. But you know, it's a difficult one to diagnose at the early stages/ But of course it wasn't my neck. Sadly it was a bit more serious.	So it took a year Sadly it was a bit more serious	Being-with-others Thrownness

5.7.3 STAGE 3: SENSE OF THE WHOLE STORY (EXPANDED)

It is understood that the meaning of the parts helps us to understand the meaning of the whole (Heidegger, 1927/1962; Gadamer, 1975). This philosophy has been carried forward by a number of researchers (Atkinson, 1998; Benzein, Norberg, and Saveman, 2001; Fleming, et al., 2003). The process has involved:

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1. Grouping together the existential themes.
2. Closer attention to the condensed statements in order to understand the meaning of the whole story.

The lifeworld experiences of one participant are given here as an example (refer to Table 12 below) of how the past is carried along by a present that is already anticipating the future (Heidegger, 1962).

TABLE 12 MEANING OF THE WHOLE STORY (JAMES)

Meaning of the whole story (James)	
Condensed statements	Aspects of existence
I used to run around in the winter time, blowing a whistle, in the summer time I'd be playing cricket, or playing tennis.	Past ways of being-in-the-world
From being an active person to hopeless care currently.	Mood
In spite of best mental efforts, this has beaten me.	Mood
Am I going to see the end of the football season, this is a tricky one.	Mortality
Making a plan for the disease is actually keeping your head fixed on the fact that you've got limited time available to do.	Mortality
Lifeworld experience This participant's story tells of existential loss because of his past ways-of-being-in-the-world, his mood in the experienced present tells of how he has been beaten by MND, of his present situation, and how he is anticipating his future: "It's a funny old situation. You sort of... it's like being in... It's like being on death row without knowing when the executioner is going to pop in".	

5.7.4 STAGE 4: IDENTIFICATION OF PASSAGES

The final stage involves identification of passages (excerpts) that are representative of shared understandings between the researcher and the participants – the fusion of two horizons (Fleming, et al., 2003). The research findings for this study have been co-created in dialogue. I understand that another researcher with a different history, culture and practice would have impacted differently on the participant, and is far more likely to have heard a different story (Finlay, 2011). The process involved:

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1. Identification of passages (excerpts) selected to bring forward what it means to be living through the illness trajectory of MND. The example below is taken from one participant's meaning of existence now he is no longer a being in the world of sport (refer to Table 13 below):

TABLE 13 IDENTIFICATION OF PASSAGES

Identification of passages (excerpts)
The only thing I'm doing at the moment is I'm watching my son play football. I used to actually referee football matches. I mean I'm a Level 1 football referee.
So I used to run around in the winter time, blowing a whistle, in the summer time I'd be playing cricket, or playing tennis. In fact I played tennis all year round. In fact it was on a... we play every Friday evening indoors, and we have been doing for twenty odd years. And as I say, it was losing my racket out of my right hand that indicated to me that something wasn't right.
It's such a huge change in your lifestyle, from being an active person, running around, and being a bit of a hopeless case currently.
So.../ In spite of my best efforts to... Mentally. / And I suppose as a competitive sportsman you always... you always feel that you have power... positive mental thought you can get... you can get by it. Er... This has beaten me.

5.8 ETHICAL CONSIDERATIONS

Addington-Hall (2002) highlights the methodological challenges of researching the health care experiences of palliative care patients. She points to issues that relate to the identification of patients in the first instance, and then to the following ethical concerns: physical problems; vulnerability; autonomy; cognitive impairment; and changes in the physical condition of the patient. The assessment of capacity and gaining consent have already been described above; in addition, in the conceptualisation of this study other ethical considerations have applied, as follows:

EMOTIONAL IMPLICATIONS

The criterion of avoiding harm is a basic ethical principle in the design of this study. However, as Hollway and Jefferson (2000) state: "can we assume that it is necessarily harmful to experience being upset or distressed? It can be reassuring and therapeutic to talk about an upsetting event in a safe context" (p.87). Researchers using a life story approach understand they must adopt active listening principles. Active listening principles involves giving a person time to express their emotions (Wengraf, 2001). Active listening principles

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are applied in the context of occupational therapy (OT) and they are applied in the research context in the same way.

RISK OF HARM

Harm must be evaluated independently of distress (Hollway and Jefferson, 2000). The participants were informed during the process of gaining consent that, should they disclose the risk of harm to self, the researcher is legally obliged to report this information to the consultant/G.P. in charge of their care or their next of kin (COT, 2010).

FATIGUE

Participants consenting to be interviewed at the neurological centre might experience fatigue following their visits to health care professionals. For this reason interviews were carried out in their homes, at times convenient for the participants, to reduce the risk of fatigue. The risks to the researcher are documented under researcher safety. It was also understood and explained to the participants that, should they become fatigued during the interview, they would be given the option to continue on another day.

RESEARCHER SAFETY

The lone worker policy was put in place. Personal details of each participant were sent to the research supervisor, only to be opened in the case of emergency. Contact was made with the supervisor at an agreed time, allowing 2 hours for each interview.

5.9 CONCLUSION

The method of data collection used for this study recognises that each participant involved in this study is a self-interpreting, temporal being with a past, present and a future (Heidegger, 1962). The participants were asked to tell their life story from when they first noticed something untoward was happening to them (Wengraf, 2001). Heidegger's phenomenology (ontic and ontological aspects of existence) was used as a philosophical framework to understand (interpret) each participant in their lifeworld (Cohn, 1997). Gadamer's hermeneutics meant gaining an understanding of the parts in order to understand the whole (Fleming, et al., 2003). This study has brought forward the two philosophical positions to understand (interpret) the meaning of existence when diagnosed with MND, a neurodegenerative life-threatening disease.

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CHAPTER 6 - INTERPRETATIONS AND FINDINGS

6.1 INTRODUCTION

This interpretation chapter provides a brief overview of the participant demographics (see Table 14) and first impressions on meeting the participants, which provide important historical, social and cultural background information (Atkinson, 1998). The aim of this study is to answer the research question: “What does it mean to be a person living through the illness trajectory of MND?” To meet this aim, Heidegger’s theoretical perspective addresses the meaning of existence as a whole, and as Atkinson (1998, p.67) states, “understanding parts of the story is important for recognising patterns and themes that connect the parts to the whole”. The interpretation of the parts are presented as the ontic aspects of being (the specific ways a person is in the world) and as the ontological aspects of being (the emotional response to MND), because Heidegger emphasises that understanding the parts brings a greater understanding of the whole (Heidegger, 1962). The interpretation of the whole stories from this study indicates how people are experiencing varying degrees of existential loss, defined from the findings as loss of past ways of being-in-the-world, loss of embodiment, loss of spatiality, loss of future. The interpretation of the parts and the whole will result in a deeper meaning of what it means to be living through the illness trajectory of MND.

6.2 PARTICIPANT DEMOGRAPHICS

TABLE 14 PARTICIPANT DEMOGRAPHICS

Name Changed	Age	Marital Status	No. of Children	Employment	Type of MND	Diagnosed	Areas Affected
James	55	Married	2 (aged 21&16)	Self employed	ALS	18 months	Upper motor neurones
Martin	68	Married	3 (adults)	Self employed	ALS	14 months	Upper motor neurones

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Charles	57	Married	Twin boys (aged 21)	Retired sales manager	ALS	2 years	Lower motor neurones
Maureen	70	Single	0	Retired carer	PMA	10 years	Upper motor neurones

6.3 FIRST IMPRESSIONS

This next section explores my perspective on what I observed on first meeting with the participants, James, Martin, Charles and Maureen. This information helps the reader to understand better the person in their everyday lifeworld, and in their context. In addition, it aids the reader in appreciating how my presuppositions had to be tempered on meeting with the participants for the first time.

JAMES

Initially, I spoke with James on the telephone in order to introduce myself and to explain further the data gathering process. I reflected in my research journal on how James was keen to know the interval between interviews 1 and 2, and he stated that he was keen to complete the research. This gave me an initial impression that I was to meet a man, perhaps no longer able to move (upper and lower limbs), who was worried about how long he had to live. Consequently, I was most surprised to arrive at James's home and for him to open the door to me. I found James to be a very handsome, tall, slim man, who was extremely welcoming. He offered to make me a drink of coffee on the condition that I added the milk, as he was no longer able to reach for the milk in the fridge. I also met his teenage son, who was asked by his father to leave the sitting room to enable us to carry out the interview. I was extremely nervous approaching this first interview because this was my first attempt at gathering life stories. The life story method requires a person to be able to reflect back on their life (illness trajectory), recall events and experiences, and tell their story uninterrupted by the researcher. I was concerned that some people may need encouragement to tell their story; however, James understood what was required of him, and immersed himself in telling his story, which he began by recounting when he first thought that something untoward was happening to him.

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MARTIN

My first contact with Martin was through the exchange of a number of emails regarding the interview process, a preferable location for the interviews, and convenient times and dates. Because I received emails from him, I thought that he must still have upper body movement, although I later learnt that his secretary types his emails. I arrived for the first interview five minutes ahead of time and the scale of his company immediately impressed me. From the signature on his emails I had already noted that the man I was about to meet had been awarded an MBE, but I chose not to research why until after the first interview had been completed. As I approached the building, Martin was just getting out of his privately registered Jaguar assisted by a woman and a man. I therefore decided to wait in my car and give him time to get into the building and become settled. I met the receptionist, who informed Martin that I had arrived before directing me up the stairs to his office on the first floor. I thought that he must still be ambulant, as he had climbed the stairs at the front of the building, as well as the stairs up to his first-floor office (I had my occupational therapy hat on at this point). Martin stood at his office door and I noted how tall and smartly dressed he was, in tweed trousers with a matching waistcoat, check shirt and tie; he presented himself as a country gentleman. I noted his hair was silver/blond, naturally curly, and he spoke with a familiar Lancashire accent. I learnt how he continues in his role as a director of a large company, and how he sustains this role through verbal communication with others. However, he is no longer able to shake hands to greet people; his arms and hands hang at each side of his body and they look heavy and oedematous. It occurred to me at this meeting that occupational therapy must surely be able to provide resting splints to prevent such uncomfortable positioning of his arms, but then I realised that I was reasoning as a therapist instead of as a visiting researcher. Martin greeted me with a warm and friendly smile and after an informal introduction he asked that I sit opposite him at his desk. He asked his grandson to make us both a cup of tea and Martin's drink was brought with a straw. I immediately felt relaxed and comfortable at the prospect of interviewing Martin; this was now the third interview I had conducted, and I felt more experienced in the interview process. Martin also looked comfortable and relaxed, and ready to tell his story.

CHARLES

I understood from the nurse specialist that Charles was on non-invasive breathing equipment, and that I should initially liaise with his wife to arrange the interview, which I did via the

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telephone, in order to confirm that Charles understood the research process and was willing to take part. On arrival at the large detached family home, I initially thought that I must have the wrong address as the home was at the top of a steep incline with many steps to its access; how could he live here? Again I was thinking like a therapist. His wife greeted me at the door, together with an extremely large dog that wished to be my best friend. Charles sat in the sitting room, his face covered with his non-invasive ventilation mask. I learnt during the interview that his wife has taken compassionate leave to take care of her husband, and his twin boys are both at university, living away from home. Charles wished for his story to be heard, but understanding his spoken words was difficult because of the breathing equipment.

MAUREEN

I spoke with Maureen on several occasions via the telephone to arrange a suitable time to carry out the interviews. Due to unforeseen circumstances, the appointments had to be cancelled on a number of occasions; Maureen was experiencing frequent falls, one of which resulted in a hospital admission. After a period of recovery Maureen agreed to be interviewed, and through our telephone calls I felt that I had got to know her. On arrival at Maureen's home I pressed the intercom button and was greeted by a male voice, who gave instructions on how to enter the first-floor flat. I entered through the door and went up the stairs (with a stair lift in situ) and entered the first-floor flat. Maureen was sat in her chair, her arm in a sling as a result of a fall, and she was operating the door intercom (hence the male voice) by a remote foot control. I was surprised at how well Maureen looked despite her recent falls. I considered how Maureen was at risk of further falls as she sidestepped to the bathroom; while standing, her trunk is in permanent flexion with her arms almost touching the floor. After the first interview, which lasted about 30 minutes, we were interrupted by the district nurse who had come to attend to the bruising on her shoulder. Once the district nurse had completed her assessment and treatment we continued with the second stage of the interview. I understood through the interview that Maureen was receiving care for all of her personal activities of daily living, but she still has her privacy in between the visits and has one carer through the night.

6.4 SUMMARY

Meeting with the participants in their environments provided first impressions; however, it could be argued that impressions were also formed before meeting the participants. First impressions are informed by roles, own life experiences, or as Heidegger would argue, by presuppositions, and a link is made to the role of researcher with several hats on in Chapter 7. Listening to the participants tell their story of living with MND, receiving health care and the impact of self and identity, brought a deeper level of understanding. The next section of interpretation refers to the ontic aspects of being.

6.5 ONTIC ASPECTS OF BEING

The ontic aspects of being are the specific ways in which a person is in the world (Cohn, 1997) and include the following existential features: being-in-the-world, being-with-others, temporality, and spatiality. These can be reviewed in more detail (See Table 7).

BEING-IN-THE-WORLD

Being-in-the-world describes our involvement with all that there is; as such, although we do enter the world from outside, we are always part of it, and this involvement Heidegger terms “care” (Cohn, 1997). The concept of “care” should not be confused with health care. Cooper (1990, p.74) further defines the concept of care:

For Heidegger, our being is one of care. This does not mean that we are constantly worrying about things, or paying solicitous attention to them. The term reminds us, rather, that we are creatures for whom the kind of life to be lived matters and is an ‘issue’.

We are “temporal” beings, as we are our history, moving from birth to death; the past is carried along by a present that is already anticipating the future (Cohn, 1997). All of the participants involved in this study talked about their past ways of being-in-the-world, their experienced present, and how they have made resolute choices for their future. For all of the participants their temporal being-in-the-world has changed significantly.

“So I used to run around in the winter time, blowing a whistle, in the summer time I’d be playing cricket, or playing tennis. In fact I played tennis all year round. In fact it was on a ... we play every Friday evening indoors, and we have been doing for

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twenty odd years. And as I say, it was losing my racket out of my right hand that indicated to me that something wasn't right." (James)

"I mean I have always been very active and I had just put a new toilet/bathroom and I had a fantastic bidet which I pulled out, well of course, this is a time I could do with it back in again." (Martin)

"I had taken early retirement, at quite an early age, at 53, and therefore I enjoyed some years of retirement before diagnosis. So therefore can be a little bit more philosophical about life, than had it hit me when working, and suddenly life had to change all of a sudden, to give up work, and to give up that particular income stream, and for my whole life to change. So that probably did make it easier to er... cope with it." (Charles)

"I used to go on holidays with [name of friend] it was nice just she helped me with things that I couldn't do. But I could walk a bit better, and I was doing everything just a normal - I wouldn't let it get me - just a normal life." (Maureen)

It appears that reflection on their past ways of being-in-the-world is more significant for James and Maureen, as they described how they used to do activities that brought meaning and purpose to their lives. Martin reflected on his past ways of being-in-the-world through reference to his loss of embodiment, whilst Charles acknowledged the fact that MND would have been harder had he still been working.

If existence is being-in-the-world, it is "spatial" – that is, part of a wider context to which it is related. But the space between different parts of this context is not measurable in feet and yards but is experienced differently at different times; what is close today can be distant tomorrow (Cohn, 1997). When Heidegger discusses space he talks about it being experienced, rather than measured as in the scientific sense. All of the participants talked about their past ways of being-in-the-world and being involved in a wider context, such as sports clubs, international travel, homes abroad, and shopping; their spatial contexts are narrowing as their disease progresses. It appears that their spatial world is now determined by the progressive nature of MND, and this was described in the following ways:

"And then I've got a visit from the OT this afternoon, this week we're going to try and examine door opening devices, because key turning is now an issue. It's funny being marooned outside your own front door, because you can't open the... I can't open the door with a key." (James)

"I have spent most of my life travelling all over the world. I used to travel. Sometimes I would go away twice a week overseas. Of course things like having to

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take your shoes off in the airport – things like that – and then I suddenly realised that I couldn't do that properly.” (Martin)

“We did two... We did three holidays... No two holidays... Three holidays the first year didn't we//to the south of France. So May, June and September. Last year we did May and July. By which time I had had a couple of falls out there and there was no way we could go in the... The second year we... we needed so much equipment, in terms of portable commodes and things that we had to take the car down, it is much further to drive all the way down to the south of France, just to the caravan.” (Charles)

“I was in [name of respiratory hospital] for a long time, they wouldn't let me come home until I decided that I'd have to have night care, and I didn't want it. I didn't want it.” (Maureen)

The excerpts chosen above provide an insight into what it means to be a person experiencing a loss of freedom to come and go in their spatial world. In addition, they have no choice but to accept equipment and adaptations in order to maintain their independence. Occupational therapists consider spatiality as part of their professional role. The assessment and recommendation of minor and major adaptations enable people to gain access to their spatial world, yet the need for adaptive equipment may be a constant reminder to people that they have MND, and indeed as experienced by Charles, it can also restrict their freedom. However, without such equipment and other adaptations, such as key turners, additional steps, rails, ramps, wheelchairs, etc., a person may be marooned in their own home and no longer be able to access the context(s) outside their home that once brought meaning and purpose to their lives. Similarly, without aids such as raised toilet seats, toilet bidets, bath seats/lifts, level access showering facilities, etc., people are no longer able to continue with their own personal hygiene. When Heidegger states that space cannot be measured in feet and yards, but is experienced differently at different times, the findings support this argument, especially for those living with MND who are no longer able to experience their past ways of being-in-their-spatial-world. For people living with MND, there is no choice but to share their home with strangers, or to accept aids and adaptations in order to remain in their own homes.

BEING-WITH-OTHERS

The idea of Being-with-others, for example family, friends, colleagues and health care professionals is a primary state of one's being, as we cannot choose to be-in-the-world without other people, although we can choose how to respond to this relatedness, which is

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also termed “inter-subjectivity” as we have a choice as to whether to concern ourselves with it or turn our back on it (Cohn, 1997). All of the participants’ stories focused on the importance of their family, friends and colleagues, as they live through their illness trajectory. Stories of their family, friends and colleagues helped them to define their identities, which brought meaning and purpose to their lives (see Table 15):

TABLE 15 MEANINGFUL AND PURPOSEFUL IDENTITIES

Participant	Meaningful and Purposeful Identities
James	Sportsman, business manager, husband, father and sporting colleague
Martin	International businessman, husband, and business colleague
Charles	Retired commercial sales manager, husband, father
Maureen	Retired carer, sister, and friend

The loss of these past identities is reflected upon in their stories and is interpreted further below (see sections 6.7 Ontological Aspects of Being and 6.9 Interpretation of the Whole). All of the participants now need help with their activities of daily living for their survival. James and Maureen are receiving help from paid carers, whilst Martin is receiving help from his wife, and Charles is receiving help from his wife and paid carers. Their stories concerning receiving health and social care were extremely varied.

“As far as receiving health care is concerned. Well I suppose it’s a bit of shock being in a situation where you have to be on the receiving end of quite a lot of health care. It suddenly makes you wake up to the... either the supreme efficiencies, or deficiencies of the NHS as a health care provider. And that er... that definitely has raised a few eyebrows.” (James)

“I have nothing but praise for the NHS, I mean when you have got potentially 70 million customers.” (Martin)

“Receiving health care, some people find it overpowering.” (Charles)

“I am getting more worked up when I have to phone people over complaints. My day care is getting better, but now they just come and do, and feed you. It’s when I get different ones, I can’t stand it. The carers have to stay overnight.” (Maureen)

The excerpts chosen above help to illustrate how people have no choice when diagnosed with MND, and have to accept health and social care provision. Health care provision involves nursing needs and functional needs, social care provision involves assistance with activities of daily living. The participants have experienced being on the receiving end of a

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multidisciplinary team of health care professionals, which Charles described as overpowering, while Maureen stated that she cannot stand having different carers coming into her home: both are experiencing an intrusion into their spatial world. James had only been receiving social care for two weeks before the interview, but Maureen does not have a choice but to accept the different carers coming into her home every day to feed her. The hospital also refused to discharge her home unless she agreed to carers staying overnight, and her loss of spatiality appears to be more profound. Without the help of carers she would not survive in her own home, but for Maureen, the choice of remaining in her spatial world alone was taken away from her. The findings from this study contradict Heidegger's concept of Being-with-others and having a choice about accepting this relatedness; three of the participants have no choice but to accept health and social care for survival in their spatial world.

In the next section the participants are still talking about health, but here they are relating the processes they experienced when diagnosed with MND. Each participant reflected upon and recalled how their illness journey started with a series of tests for MND (blood tests, electromyography (EMG) nerve tests, and magnetic resonance imaging (MRI) scans), before being diagnosed with MND. The time taken to receive their diagnosis was significantly different for each participant. Martin and Charles chose to be diagnosed privately and received their diagnosis within days of undergoing the tests for MND; James and Maureen, on the other hand, were admitted into NHS hospitals for days and weeks, where they underwent the same tests before finally being diagnosed. James and Maureen had also been involved in the teaching of medical students, which meant being observed by a number of students whilst in hospital.

“And I think I was in hospital for Monday to Thursday, I think I was discharged on the Thursday. But when I actually think of the tests that I had done, had I been able to have them done concurrently I could probably have done them all in a day, or a day and a half. But obviously it had to fit in with all the test equipment, and the time involved, and the scheduling of the department.” (James)

“So I arranged for a private consultation with [name of consultant] at the [name of hospital], which I got in 2 to 3 days. He then arranged for an MRI scan on a Friday evening with the results then to be analysed on the Monday morning.” (Martin)

“Going private did make a difference, that was a Thursday and I was expecting an answer by Monday morning. Unfortunately er... I did get that answer and it was something totally out of the blue to what I expected it to be. The fact it turned out to

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be a terminal disease of which I knew very little to zero other than everybody's experience of Stephen Hawking really.” (Charles)

“Then I went in and then they did a lot of tests, like all the nerve ends of your body, and all that, and a lot of other tests. You know I can't just remember all of them, but I had a lot of tests. And then they said, ‘Well, you go home now and then we'll send for you, because we want you to have a full scan’. I had a full scan and then I went back, and then they said we'll have you in for five days. Any way they did all tests on me and that five days lasted for about eight weeks.” (Maureen)

James and Maureen were admitted into acute NHS settings where they were diagnosed with MND. This is an issue, as the other two participants received diagnosis within days when going private, and it must be noted, from the same neurological consultants at the MNDA Care Centre. They were also subjected to student health care professionals observing their physical symptoms. Their thoughts on being observed are varied, as follows:

“When I was in [Name of hospital] being diagnosed there was an awful lot of people came in to look at me, because I think I have quite physical fasciculations, which are a diagnostic indicator of things not going well.” (James)

“He said ‘you'll be going under [name of hospital], but I was still in a while after that. And then I had all the students around me seeing, because you've got to let people learn, haven't you? I don't mind that.” (Maureen)

Student health care professionals do have to learn about the physical symptoms of MND, but the question is whether people admitted to the acute NHS setting are given the choice and control. The findings above are suggesting that for people given a diagnosis of MND that choice is taken away from them.

These excerpts were chosen because they highlight how people are experiencing the “efficiencies and deficiencies” of the NHS as a health care provider. This is a small sample, and yet the two patients choosing private health care options to undergo a series of neurological tests waited only days for their diagnosis. In sharp contrast, two of the participants admitted to the acute NHS setting underwent the same series of neurological tests, but waited days and weeks for their diagnosis. In addition, they had to endure a lot of people coming in to observe their presenting symptoms.

Throughout their illness trajectory, all of the participants accepted the management of their condition from their local MND Care Centre, although access to the centre is becoming

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increasingly difficult for James, Charles and Maureen. The participants discussed the care they have received, which has been primarily focused on monitoring their physical needs: dyspnoea (weakness of intercostal muscles and diaphragm responsible for respiratory functioning); dysphagia (swallowing problems); progressive weakness; pain; cough; insomnia; reduced mobility; and reduced activities of daily living. The participants describe their care as follows:

“They’re obviously very keen to ask me about my swallow, and my breathing. And we all know the reason for that. [Clears throat] I have lost [sigh] a stone and a half in weight.” (James)

“Well, to be honest, they are only monitoring it. That's all they are doing. For instance, they have been monitoring my blood gas levels and things like that, and any assistance I need on breathing, although my lungs are okay. They only suggested putting a peg in my stomach and things like that.” (Martin)

“Initially as well as the MND centre, which had good signposting of things, you might see the... I think we saw the physiotherapist and the OT and various people the first time we went, but they then... But the local rehabilitation team tend to send their own physiotherapists. Now when I go to the MND centre I don't spend very long with those individuals because I have really got everything I need locally.” (Charles)

“I had the speech therapist, and she assesses your food and how you eat, and what I eat. She came about a fortnight ago. I very rarely see a Social Worker, and I am a bit annoyed with them. I don't want to see them. But they will say ‘Who comes to see you?’ I say ‘No one only’... I have the nurse and my physiotherapist. I have a new OT, I am just beginning to get used to, but I have to keep mithering and mithering for things. I don't want me home being like hospital, I definitely don't.” (Maureen)

These excerpts were chosen because the participants are all describing how their MND is monitored and managed, either at the MND Care Centre or in the community. They have all experienced health care that has been focused on the following physical and functional needs: their ability to breathe; their weight; their swallow and speech; their posture and mobility, and their ability to remain independent with personal activities of daily living in their own homes. Martin was keen to talk about his prognosis with the health care professionals and stated:

“I mean I do try and ask them, er you know, when I am going to die, and is it going to be pneumonia, is it this? And they all seem to be very reluctant to communicate that. And I think they are not used to people being open and straight you see.

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Whereas I would far rather know I mean er... I mean I think people... Because it is a terminal disease are always a bit frightened, they have to have somebody with them at first, they are frightened of being politically incorrect. Which is... You know they are frightened of ticking the wrong box. Of course he doesn't bother now, I... I'd rather he speak frank and open.”

6.6 SUMMARY

Heidegger's philosophical concepts of being-in-the-world, namely temporality (past, present and future), spatiality (space/activities), and being-with-others (family, friends, colleagues and health care professionals), helped to examine more closely what the participants' specific ways of being-in-the-world through time were, and also their responses to Being-with-others. All of the participants involved in this study have their own unique way of being-in-the-world and response to being diagnosed with MND and Being-with-others. However, despite this uniqueness, generalisations can be drawn, such as that the health care they have received has focused on the participants' physical and functional needs. The findings suggest that the four participants involved in this study are experiencing varied degrees of health care provision impacting on them in their spatial world:

- Duration of diagnosis
- Context of diagnosis and experiences
- Health care that focuses on their physical and medical needs
- Loss of their spatial world

The next section refers to the ontological aspect of being, which looks at the participants' emotional responses to MND.

6.7 ONTOLOGICAL ASPECTS OF BEING

The ontological aspects of being refer to the intrinsic aspects of being, which are “given” and “unescapable” (Cohn, 1997). The concepts of thrownness, embodiment, mood and mortality will be applied (See Table 7).

THROWNNESS

Thrownness refers to the limits of our control over existence; as such, life is conditioned in many ways, and from birth onwards we find ourselves in situations not of our choosing (Cohn, 1997). Yalom (1980) stated that Heidegger used the concept of thrownness to explain “an emotional response to finding oneself inserted, without consent into an existence not of our choosing” (p.358). To relate being diagnosed with MND with thrownness, it can be argued that we are all anticipating our deaths, but in MND people have to face the reality more abruptly. The participants’ emotional responses to finding themselves diagnosed with MND is expressed in the excerpts below.

“The interesting thing is, of course, the stock answer, when people ask how long they’ve got, is three to five years, and I’m never certain whether that three to five years is from diagnosis, or from actual onset of the disease. So just being silly, if you think the first noticeable symptom occurred in October, ’09, I must have had... I must have had the disease prior to that, and... Let’s say June, and since that time, as I say, the rate of degradation, or degeneration, has been relentless.” (James)

“When news suddenly comes out of the blue and it very much was so, er... The period after that you are in tatters really, both yourself and your immediate family.” (Charles)

“My past history has probably given me the resolve to fight the disease in the best way I can.” (Martin)

“I came home and it didn't seem to bother me. I didn't come home and sit and think, oh you know!” (Maureen)

All of the participants are in a situation not of their choosing, but their responses to being diagnosed with a life-threatening illness are varied. Thrownness appears to be more profound for James and Charles; both have adult children and are losing their once projected future with them, which may be the reason. The loss of their projected future was emphasised by James and Charles.

“My family can’t all put their lives on hold just because I’ve got a problem. And I’m sure, if you asked them, they would say, ‘Well we prefer not to plan it’, but you can’t sidestep that. And erm... They are understandably saddened by it. But nobody’s... you know, much as the local opinion might be that this is huge cause for people to suffer from depression, we’re not... Yeah, we’re emotionally resilient enough for that not to be an issue.” (James)

“But what I do feel is incredibly sad that I won’t be around to see things in the future and to enjoy my retirement with my family etc.” (Charles)

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In sharp contrast, Martin and Maureen are in their sixth and seventh decades, although this does not imply that they are any less active; rather, that being diagnosed with a terminal illness at this age may be easier to accept because people may have lived a fulfilling life. Both talked about their faith and how this has helped them to come to terms with being diagnosed with MND. Perhaps the Catholic faith gives people the ability to cope with their finitude.

EMBODIMENT

Embodiment also relates to the non-physical aspect of being such as the psychological, social and spiritual dimensions (van Deurzen and Arnold-Baker, 2005). Heidegger's focus was on ways of being: physical, psychological, social and spiritual (Inwood, 1997). MND is progressive, and the four participants involved in this study each have observable loss of either upper motor neurones, lower motor neurones, or both. James has lost some of his upper motor neurones, impacting on his ability to lift his arms above a certain height, and although he is still ambulant, his speech is slurred and swallowing is becoming difficult. James relates to the physical, psychological and social impact of MND in the following way:

“I do not have to modify my eating habits greatly, erm... Jacob's Cream Crackers don't appear on the menu very often now, unfortunately, because of the choke hazard. And I'm obviously a little bit reluctant to find myself eating on my own in the house, just in case I do have a problem. Erm... But that's easily managed by making sure there's somebody here, which is what Social Services are doing. Erm... I can still just about lift a pint to my... Yeah, so... But everything is very close to my body.”

Martin has total loss of his upper motor neurones: he can no longer move his arms, and his head is supported in a neck brace, although his speech is not affected, nor is his swallowing or breathing. Martin also relates to the physical, psychological, and social impact of MND:

“The slowly loss of the muscles that I have had in my arms was extremely painful; psychologically your mind thinks you can do it. You suddenly realise that you really have to be with somebody all the time. It is like when you wake up at night and you want to go to the toilet, you still think that everything is okay until you try and get out of bed and then... My wife has to push me out and then when I... I just sit up on the bed and then I can manage from the sitting up position.”

Charles has total loss of his lower motor neurones: he can no longer move his legs, he has a little movement of his trunk and arms, and he is on permanent non-invasive breathing

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equipment; however, his speech and swallow are not affected. Recently, Charles asked to see what he looked like in the mirror and he was shocked at the reflection looking back at him.

“When you are actually in this situation you don't quite know what you look like, and I say that in a slightly humorous way, but because my wife has been dressing and sort of brushing my hair and everything, and there's no mirrors at wheelchair height in the bedroom or anything, I suddenly realised what I looked like with my ventilation on. But she showed me I said ‘Bloody hell, I look a right state’, but you don't realise it at the time. But you don't think you are in a wheelchair, you think I am just me, and I am here, and I am sitting like in a chair, whereas people see me wheeled around and wheels, you can't see the wheels when you are in the wheelchair. So you perhaps don't get as depressed as you might do, if you could all the time see that slightly pathetic situation that you are becoming.”

Maureen has total loss of her upper motor neurones: she can no longer move her arms, and her head is supported in a neck brace; although her speech is not affected, she is having some difficulty swallowing and is on non-invasive breathing equipment during the night. When sitting, Maureen has an upright posture and is able to operate remote controls with her foot in order to open the door to guests and to answer the phone. She acknowledged how her MND is progressing:

“But now I've had to stop it [going out into the world], since Friday. I have decided/ No. I realised because I can't walk and I was going and I thought no because I am falling so much... and they are worrying how I am and all that. So I said ‘No. I think I've had enough now.’”

Heidegger acknowledges that we do not usually attend to our bodies as long as they are in good working order; however, the participants involved in this study have no choice but to attend to their bodies because they are experiencing a loss of embodiment. Each participant summarised their loss as follows:

“As I say, the rate of degradation, or degeneration, has been relentless.” (James)

“But of course it is a very degrading disease. I mean I can't do such basic things for myself, and you feel humiliated. I mean you can't feed yourself. You can't go to the toilet yourself properly.” (Martin)

“But also cruel although it is, it is less cruel if you have got a partner, or a full time carer who cares, if you see what I mean.” (Charles)

“You don't want anything in the shops and now I know my shape I can't wear anything properly. A lot of my clothes I give to [hospice W] charity. But I have

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never had on some of them good clothes because I know how my shape has gone.”
(Maureen)

The impact of MND on their embodiment is expressed as an emotional response, such as degrading, humiliating and cruel, but MND also results in body disfigurement. Charles acknowledged that he has chosen not to look at himself in the mirror for a long time, and it may be because of the fear of the reflection looking back at him. When Maureen discussed knowing her shape had gone, she was providing clues to her past identity, a lady who used to finding meaning and purpose in shopping for nice clothes to wear. The impact of MND on embodiment (physical, psychological, social and spiritual ways of being) can be applied to all the participants involved in this study. Loss of embodiment has meant for each participant an inability to continue with their past ways of being-in-the-world: playing sports, drawing for a living, planning a future with sons, going out with sister and friends. For all the participants loss of embodiment is: not being able to feed oneself independently, having to have carers come in to feed you, and needing to drink through straws, like a child. For one participant it is not being able to scratch one's own head, using the railings, or the desk to scratch upon. For two of the participants it has meant having to accept a toilet bidet to help wash and dry oneself after toileting, or for one participant taking one's brother along to help with personal hygiene needs when away on business. For two participants it has meant acknowledging that one's lungs are no longer functioning, and having to accept non-invasive ventilation in order to stay alive. This has meant adaptation of the self in the physical world. For one participant a loss of embodiment has meant pain and discomfort.

A loss of embodiment has evoked psychological responses to being dependent on others, such as embarrassment, loss of dignity, degradation, fear for physical safety, sadness, altered self-image. A loss of embodiment has involved not being able to act in their social world: sport, business, and with family, friends and work colleagues. A loss of embodiment has impacted on their spiritual self, and not in a religious way, but on their ways of being: being an active sportsman, being an international businessman, being a husband and father, being a parishioner, sister and friend. A loss of embodiment has meant the participants are no longer able to act in their spatial world, and are having to accept help to do so. A loss of embodiment has meant that their once projected future is no more: they are no longer able to enter sporting tournaments, travel to maintain business relationships, plan for retirement with

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the family, go on holidays, go shopping, and go to church. A loss of embodiment involves planning for a very different future, a future where their being is no more.

MOOD

Mood describes the affective aspect of the experience of being-in-the-world; mood does not respond to what it meets, it also discloses it (Cohn, 1997). Heidegger is referring to the fact that human beings are always in one mood or another, which is how we learn about ourselves. The participants' responses to their thrownness has already been interpreted, and it has been acknowledged that James's and Charles's emotional responses to being diagnosed with MND in their fifties has had a profound impact on their lives; in contrast, Martin and Maureen, in their late sixties and early seventies, have managed to remain positive throughout their illness trajectories. Closer attention to the concept of mood further emphasises their contrasting levels of emotional response to MND:

“So.../ In spite of my best efforts to... Mentally. / and I suppose as a competitive sportsman you always... you always feel that you have power... positive mental thought you can get... you can get by it. Er... This has beaten me.” (James)

“I mean you have got to be positive and move forward, but I mean I think everybody's approach is different to it. The support they get at home is probably different.” (Martin)

“I have never felt any depression for the full period, because depression to me is usually defined as a medical condition. But what I do feel is incredibly sad that I won't be around to see things in the future and to enjoy my retirement with my family etc.” (Charles)

“People are so kind and you've seen so much of cruelty and what people have and all of that. You just have to think positive.” (Maureen).

Heidegger's concept of mood is an intrinsic response to the “givens” in life and how we respond to them. These givens in life may be accepted or denied, and it is possible to be in denial of what we experience as demands and threats could lead to disturbances (Cohn, 1997). For the first year following diagnosis James was able to continue in his world of sports and Charles continued going on holiday with his family, but as MND progressed these preferred ways of being became more difficult. It appears that MND can no longer be denied because it is already a reality. Both James and Charles are living with the reality that their MND is progressing each day, because each day they lose use of their upper or lower body or both. Both James and Charles are living with uncertainty, as expressed below:

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“Well, funnily enough, one of the things that erm [Name of consultant], at my last clinical appointment, put me... gave me a referral to [Name of hospice consultant], I think he’s in palliative care at the hospice, and has a clinic at [Name of hospital], but bearing in mind it’s April, I haven’t heard a dicky bird since. But yeah, the time is ticking against me. If they don’t get on with it I’ll be a name on a list of deceased patients, rather than somebody that is on a palliative care list.” (James)

“But uncertainty about your future and dying, you know you are going downhill, you know roughly what rate, and you will cope with it when it happens sort of thing. So I guess you have got a whole bloody chapter on uncertainty in some people.” (Charles)

These two excerpts bring forward the different levels of anxiety experienced; James is frightened of time running out before he has seen the specialist palliative care team, whilst Charles acknowledges his MND is progressing, and his uncertainty is about the future and dying. Charles has acknowledged that he will be supported by the local Macmillan nurses in the community and hopes that he will be supported to die peacefully and comfortably. In contrast, James is still waiting to be seen by the specialist palliative care health professionals.

FUTURE

A person projects their future because of their awareness of the inevitability of death; this is our ultimate limitation which one can choose to deny or accept as an intrinsic aspect of living (Cohn, 1997). The participants involved in this study discussed their experienced present and anticipated future, and how they have started to make plans for their future and beyond. None of the participants know when they will die, and their levels of acceptance are varied. They related to their finitude in the following ways:

“But for instance, simple things like sleep... I normally sleep very well, but you are forever waking up thinking I am dying, what is this all about.” (Charles)

“Not many people get the opportunity to go to their own wake, and you have a chance to prepare yourself both spiritually and sort your personal affairs out.” (Martin)

“It was a thing [funeral] I never liked talking about, and I was amazed that I have done it. I feel a lot better. I mean I could live them out [chuckles].” (Maureen)

The excerpts above show the varying degrees of acceptance and denial demonstrated towards their experienced present and their anticipated future. It is unclear what he meant when Charles expressed his fear of dying. In sharp contrast, Martin is almost acknowledging

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gratitude for being able to re-engage with his spirituality, and he also feels that he is living on borrowed time; he has made a number of resolute choices not to go into the hospice but to die in his preferred place, either at home, in his car or in his office chair. Maureen has been living with MND for 10 years and has found talking about her mortality difficult; she has only recently been involved with the hospice and has made plans for her future. It has to be acknowledged that not everyone faced with a life-threatening illness has this amount of time to plan their future, for example people who suffer a fatal heart attack. Even people living with PBP MND (see Table 1) have an illness trajectory limited to months, and therefore may not have the time to make their needs, priorities and preferences known before they lose their ability to communicate them. The counterargument to this is clearly expressed by James, who described his experienced present and anticipated future as being a prisoner waiting for his death.

James, Martin and Charles talked about their views on ending their own life. They have an awareness of the possibilities available to people living with MND, and how some choose assisted suicide by contacting the Dignitas Clinic in Switzerland.

“You sort of... it’s like being in... It’s like being on death row without knowing when the executioner is going to pop in. Anyway, we shall be sorting that one out.”
(James)

“I am quite religious and of course I’ve... I would certainly never consider going to Switzerland or anything like.” (Martin)

“It’s worth documenting that people do consider a Switzerland type of approach initially.” (Charles)

Although Charles’s statement may be considered a generalisation, it does highlight the fact that this small sample group have varied beliefs on what they do with their lives. The above excerpts bring forward three very different approaches to the Dignitas route: whilst James is determined to act, for Martin it is not an option, and Charles acknowledges that this was once a possible option, at least in the initial stages following diagnosis.

6.8 SUMMARY

Heidegger's philosophical concepts of thrownness, embodiment, mood and mortality have helped to examine closely the intrinsic aspects of being which are given and inescapable, from the time of diagnosis and through the illness trajectory. The participants involved in this study appear to have varied emotional responses to the "givens" in their lives. The interpretation of the whole stories helps in assessing how MND has impacted on their lives (past, present and future). The findings suggest that the four participants involved in this study are experiencing varied degrees of emotional responses to:

- Being thrown into the world of MND
- Their present (embodiment and spatiality)
- Finding themselves in one mood or another
- Their future

The next section of the findings will concentrate on the whole.

6.9 INTERPRETATION OF THE WHOLE

These findings are the stories recounted by the participants and are presented under four headings: loss of past ways of being-in-the-world, loss of embodiment, loss of spatiality and loss of future.

LOSS OF PAST WAYS OF BEING-IN THE-WORLD

According to Heidegger, the world is a whole sphere (or context) that organises all of our interests; "being successful" in our world helps us to define our identities and helps us to define our own being, whether authentically or inauthentically (Polt, 1999). Although all of the participants discussed loss of past ways of being-in-the-world, it appears on closer inspection of James's whole story that he is expressing this loss more deeply. When James reflected on his past sporting activities, he presented pictures of himself doing the activity. Closer attention to his expressions of mood and mortality helps in understanding his emotional response to his change in lifestyle. He reflected on his experienced present, and how the future has no place for him now that he has given up his fight against MND; so he is instead planning the future for his family after his death. For James's lifeworld perspective, see Table 16 below:

TABLE 16 JAMES'S LIFEWORLD

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James's lifeworld		
Meaning unit	Condensed statements	Aspects of existence
"The only thing I'm doing at the moment is I'm watching my son play football. I used to actually referee football matches. I mean I'm a Level 1 football referee". "So I used to run around in the winter time, blowing a whistle, in the summer time I'd be playing cricket, or playing tennis. In fact I played tennis all year round. In fact it was on a... we play every Friday evening indoors, and we have been doing for twenty odd years. And as I say, it was losing my racket out of my right hand that indicated to me that something wasn't right."	"I used to actually run around in the winter time, blowing a whistle, in the summer time I'd be playing cricket, or playing tennis."	Past ways of being-in-the-world
"It's such a huge change in your lifestyle, from being an active person, running around, and being a bit of a hopeless case currently."	"From being an active person to hopeless case currently."	Mood
"So.../ In spite of my best efforts to... Mentally. / And I suppose as a competitive sportsman you always... you always feel that you have power... positive mental thought you can get... you can get by it. Er... This has beaten me."	"In spite of best mental efforts, this has beaten me."	Mood
"Erm... I am getting on with life it's the only way to go. And of course that's being amply demonstrated by the fact that the football season has started, Grand Prix season has started, football season is boiling up to a fantastic climax, and you just think to yourself, well, hm, am I going to see the end of the football season? Or am I going to see the... Who knows? This is a tricky one."	"Am I going to see the end of the football season? This is a tricky one."	Mortality
"So, you know, the person that is getting to the bucket list of things they want to do before they die, you could fill up the whole of the rest of your life doing that, and forget all the tidying up parts, which is what I	"Making a plan for the disease is actually keeping your head fixed on the fact that	Mortality

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consider that advice to be aimed at. Making a plan for yourself is to enjoy whatever you want to do. Making a plan for the disease is actually keeping your head fixed on the fact that you've got limited time available to do... Yeah."	you've got limited time available to do."	
Interpretation of the whole James's story tells of existential loss because of his past ways-of-being-in-the-world; his mood in the experienced present tells of how he has been beaten by MND, of his present situation, and how he is anticipating his future: "It's a funny old situation. You sort of... it's like being in... It's like being on death row without knowing when the executioner is going to pop in. Anyway, we shall be sorting that one out".		

LOSS OF EMBODIMENT

Heidegger notes that "only when machinery suddenly breaks down do we become aware of its functioning" (Yalom, 1980, p.171). Loss of embodiment, although observably more profound for Charles, who is now on non-invasive ventilation, and Maureen, who is doubled over when standing, is actually discussed more by Martin. When Martin reflects on his past activity and spending most of his life travelling the world, he does not look at this as a loss, but as a meaningful and purposeful aspect of his being-in-the-world of business. As he stated, his past experiences have given him the resolve to fight the disease, and his mood is positive. However, the experience of loss of embodiment is expressed when he reflected on the impact of MND on his left hand, the hand he used to draw with as an architect, and the pain he has experienced through this loss. Martin is grateful for living on borrowed time and his lifeworld perspective is shown in Table 17:

TABLE 17 MARTIN'S LIFEWORLD

Martin's lifeworld		
Meaning unit	Condensed statements	Aspects of existence
"I mean I have always been very active and I had just put a new toilet/bathroom and I had a fantastic bidet which I pulled out, well of course, this is a time I could do with it back in again."	"I mean I have always been very active."	Past ways of being-in-the-world

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“I have spent most of my life travelling all over the world. I used to travel. Sometimes I would go away twice a week overseas.”	“I have spent most of my life travelling all over the world.”	Spatiality
“My past history has probably given me the resolve to fight the disease the best way I can. I suppose I am always a little bit concerned when people seem to think that the only terminal disease is cancer.”	“My past history has given me the resolve to fight the disease.”	Temporality
“I mean you have got to be positive and move forward, but I mean I think everybody's approach is different to it. The support they get at home is probably different.”	“I mean you have got to be positive and move forward.”	Mood
“The first time I suspected there was something wrong, was I am or I was left handed, whereas now I am not any handed of course, but I was left handed. But I started dropping things and being clumsy with my right hand, um I knew it was out of character; actually I have been blessed with a lot of skill, in being able to do anything mechanical with my hands for drawing.”	“I was left handed, whereas now I am not any handed of course.”	Embodiment
“The slowly loss of the muscles that I have had in my arms was extremely painful. Initially I was diagnosed with [Gabapentin] to ease the pain, but it didn't really make much difference until the hospice prescribed morphine.”	“The slowly loss of the muscles that I have had in my arms was extremely painful.”	Embodiment
“Well MND... I mean it changes your entire perception of life. The things that you think you can do you can't. Psychologically your mind thinks you can do it. You suddenly realise that you really have to be with somebody all the time.”	“I mean it changes your entire perception of life.”	Embodiment
“It is like when you wake up at night and you want to go to the toilet, you still think that everything is okay until you try and get out of bed and then... My wife has to push me out and then when I... I just sit up on the	“When you wake up at night, you still think that everything is okay until you try and get out of bed and then...”	Embodiment

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bed and then I can manage from the sitting up position.”		
“I mean I am actually now over what time span I expected to have so I am on borrowed time effectively aren't I?”	“So I am on borrowed time effectively aren't I?”	Mortality
Interpretation of the whole Martin's story is one of resolve to fight the disease. Despite his physical loss in his upper body, and his pain, he still goes into his company every day to maintain his ways of being-in-the-world of business. He anticipates his future as a struggle, but despite this, he would prefer not to have to go into the hospice, but to remain in his own home. He expresses gratitude for living on borrowed time in the following way: “I mean there are not many people get chance to go to their own wake, and you have a chance to prepare yourself both spiritually and sort your personal affairs out”.		

LOSS OF SPATIALITY

According to Heidegger, our past and our future are meaningful to us in everyday life because they are relevant to our current practical concerns, where we keep track of time not by using numbers, such as 6am, 12 noon, and 10pm, but in terms of what it means to our activities (Polt, 1999). Loss of spatiality, although relevant for all of the participants, was experienced more acutely by Maureen when she described how she used to do the activities that once brought meaning and purpose to her life. Her mood is one of fight and determination, and in the experienced present Maureen keeps track of time in terms of her existence: time to get up; time for a district nurse visit; time for her carers to arrive to feed her lunch/tea; time for her medication; and time for her carer to arrive to prepare her for bedtime. The loss of respiratory functioning during the night has meant that, reluctantly, Maureen had to accept night carers in order for her to survive in her own home. This acceptance of carers in her home overnight appears to be an intrusion into her spatial world. Ashworth (2006) also found that for people living with Alzheimer's disease the past and future has no place, as people are focused on their present spatial world. People living with both illnesses are reliant on their carers (lay or professional) for survival in their spatial world. Maureen's lifeworld perspective is presented in Table 18 below:

TABLE 18 MAUREEN'S LIFEWORLD

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Maureen's lifeworld		
Meaning unit	Condensed statements	Aspects of existence
"I used to go and have my hair done in town and just do things normal, and then I was getting that way that I couldn't get on the bus properly and things like that."	"I used to go and have my hair done."	Past ways of being-in-the-world
"I used to go on holidays with (name of friend) it was nice just she helped me with things that I couldn't do. But I could walk a bit better, and I was doing everything just a normal - I wouldn't let it get me - just a normal life."	"I used to go on holidays."	Past ways of being-in-the-world
"But I won't give in, in that way, and then I'm under [name of respiratory hospital] and all with the complaint, because it affects your sleep and my lungs weren't functioning."	"But I won't give in."	Mood
"My day care is getting better, because like when my first carer left, she went to Australia, she was like my daughter. She always said I was like a second mother. And she did care. But now they just come and do, and feed you, and all that."	"My day care is getting better."	Spatiality
"But I've been fortunate really in care, but at first, no. It's when I get different ones, I can't stand it. You know? I know you have to have different ones sometimes, but now it's getting alright."	"It's when I get different ones, I can't stand it."	Spatiality
"The carers have to stay overnight because sometimes my breathing equipment can drop out, and they are here because I can't put things back, you know, pick or anything."	"The carers have to stay overnight."	Spatiality
"I never wanted them, but I would be lost without them."	"I would be lost without them."	Spatiality
"I have sorted my funeral and all that. And my sister has accepted it now."	"I have sorted my funeral and all that."	Mortality
Interpretation of the whole Maureen's story is one of fight and determination not to give in to her MND, despite her observed deteriorating loss of embodiment and her spatial existential concerns. She is making plans for her future, which has been difficult: "It was a		

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thing I never liked talking about, and I was amazed that I have done it. I feel a lot better. I mean I could live them out [chuckles].”

LOSS OF FUTURE

Authentic existence involves facing up to our own mortality, the finitude of our possibilities, and not worrying about when our demise will come, but rather accepting and choosing in light of this finitude (Polt, 1999). Although all of the participants discussed their loss of future, it appears on closer inspection of Charles’s lifeworld that he is experiencing his loss of future more profoundly. Charles reflected on his loss of future with his boys and his mood is one of sadness for this loss. He also reflected on his anticipated future and how he will be supported by the local Macmillan nurse. In addition, he is in the process of discussing and completing an advanced care plan and advanced directive, making known his needs, preferences, and priorities for his end-of-life care. For Charles’s lifeworld perspective, see Table 19 below:

TABLE 19 CHARLES’S LIFEWORLD

Charles’s lifeworld		
Meaning unit	Condensed statements	Aspects of existence
“I had taken early retirement, at quite an early age, at 53, and therefore I enjoyed some years of retirement before diagnosis. So therefore can be a little bit more philosophical about life, than had it hit me when working, and suddenly life had to change all of a sudden, to give up work, and to give up that particular income stream, and for my whole life to change. So that probably did make it easier to er... cope with it.”	“I had taken early retirement.”	Past ways of being-in-the-world
“But what I do feel is incredibly sad that I won’t be around to see things in the future and to enjoy my retirement with my family etc.”	“But what I do feel is incredibly sad.”	Mood
“There is actually a local Macmillan nurse who has got expertise in MND and she has	“She is going to be great for me as time goes by.”	Mortality

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come, she is a lovely lady and she is going to be great for me as time goes by.”		
“But uncertainty about your future and dying, you know you are going downhill, you know roughly what rate, and you will cope with it when it happens sort of thing.”	“You know you are going downhill.”	Mortality
“So in the end certainly we are in the midst of putting together the... the/ Living Will type thing, personal directive.”	“We are in the midst of putting together the living will type thing, personal directive.”	Mortality
“There will come a time when you think I had enough, and therefore that will be probably the time to stop feeding, stop this and please make me as comfortable as possible in the period whilst I fade away type of thing.”	“There will come a time when you think I had enough.”	Mortality
Interpretation of the whole Charles’s story does not focus on the concern for the loss of his past, or for himself in the present; despite being on non-invasive ventilation and unable to move independently, his existential concern is for his family and their future. He states: “I look forward to see the kids back from university, to know that we are getting on all right”.		

6.10 SUMMARY

A hermeneutic phenomenological approach recommends paying close attention to the meaning of the parts in order to understand the meaning of the whole (Atkinson, 1998; Fleming, et al., 2003; Heidegger, 1962, Gadamer, 1975). Understanding the meaning of existence has involved interpreting the participant’s ontic aspects of being (the specific ways in which a person is in the world), and their ontological aspects of being (the intrinsic aspects of being which are “given” and inescapable) (Cohn, 1997). Both the ontic and ontological aspects of being are part of the existential phenomenological approach used in this study to understand what it means to be a person living through the trajectory of MND. It is understood (interpreted) that each participant has experienced varied degrees of existential loss, defined from these findings as loss of past ways of being-in-the-world, loss of embodiment, loss of spatiality, loss of future. The following are examples of the aspects of loss that appear more profound for the individual participants:

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- Loss of past ways of being-in-the-world, because James is no longer able to take part in the sporting activities that once brought him meaningful and purposeful identities.
- Loss of embodiment, because Martin is no longer able to use his hands, his tools for drawing that once brought him meaningful and purposeful identities.
- Loss of spatiality, because Maureen is no longer able to go out into the community that once brought her meaningful and purposeful identities, and she is now reliant on carers for her survival in her spatial world.
- Loss of future, because Charles is no longer able to look forward to a future retirement with his family that would have given him meaningful and purposeful identities.

Despite the different aspects of loss that appear more profound for each participant, there are shared patterns of experiences across the cases, for example embodiment is now experienced as: altered self-image, and fear for physical safety (see Table 20 below):

TABLE 20 EMBODIMENT IS ALTERED SELF-IMAGE AND FEAR FOR PHYSICAL SAFETY

Altered self-image	<p>“I have lost [sigh] a stone and a half in weight. And I wasn’t a... you know, my BMI index was spot on for my height, so I’m on the low side of it now” (James).</p> <p>“I’ve always had a good sense of humour over the complaint and of course it is probably very difficult for some of these doctors and nurses to probably have the same. Because I told them that since my neck muscles have gone I have got a part time job playing Quasimodo at the local playhouse theatre and they have put... I think it is difficult for them to know how to take a joke really” (Martin).</p> <p>“When you are actually in this situation you don't quite know what you look like, and I say that in a slightly humorous way, but because my wife has been dressing and sort of brushing my hair and everything, and there's no mirrors at wheelchair height in the bedroom or anything, I suddenly realised what I looked like with my ventilation on. But she showed me and I said ‘Bloody hell, I look a right state’” (Charles).</p> <p>“But I have never had on some of them good clothes because I know how my shape has gone. And when you look at yourself you think oh no, you know. I do buy bits, tops and that because I don't want to go out like that you see” (Maureen).</p>
Fear for physical safety	<p>“I am frightened of going anywhere on my own” (Martin).</p> <p>“But I would say the last twelve months, two years I've started having a lot of falls, so then I had to stop going because they were worried” (Maureen).</p>

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Spatiality is experienced as: dependency and limited choice (see Table 21 below):

TABLE 21 SPATIALITY IS DEPENDENCY AND LIMITED CHOICE

Dependency	<p>“Yeah. Social services come in twice a day to help with shaving, washing, dressing, cooking breakfast, doing my teeth” (James).</p> <p>“I am frightened of going anywhere on my own. I mean I can't pull money out of my pocket for instance so... my bus pass or whatever. So you are really totally dependent on... Well I am now” (Martin).</p> <p>“The carers have to stay overnight because sometimes my breathing equipment can drop out, and they are here because I can't put things back, you know, pick or anything. I never wanted them, but I would be lost without them” (Maureen).</p>
Limited choice	<p>“Anyway we have had a fantastically intricate [Bio-Bidet] fitted, because hand dexterity for toileting isn't great” (James).</p> <p>“It's probably good time to look at the total cost of... situation, and in a way it links back to this thing about whether you do harm to yourself. I think that one's life does have a value and if it suddenly was going to cost, we have a house that's worth take a figure of three hundred thousand, and you end up having to spend ten thousand pounds on a through floor lift from one floor to another, and fifteen thousand for a totally new bathroom. Then the cost when you have passed away for those things to be cleaned up, tidied up, to make good... to sell the house, if you had any income at all... sorry if you have any capital at all, you could end up spending that sum of money” (Charles).</p>

There is a variance in mood/attitude to the existential ‘given’ of living with a life-threatening illness: whilst two of the participants remain positive, one participant reported feelings of hopelessness, and one participant feelings of sadness (see Table 22 below):

TABLE 22 MOOD IS THEIR EMOTIONAL RESPONSE TO MND

Other expressions of distress	<p>“It's such a huge change in your lifestyle, from being an active person, running around, and being a bit of a hopeless case currently” (James).</p> <p>“I have never felt any depression for the full period, because depression to me is usually defined as a medical condition. But what</p>
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	I do feel is incredibly sad that I won't be around to see things in the future and to enjoy my retirement with my family etc.” (Charles).
Positive meaning in life	“I mean you have got to be positive and move forward” (Martin). “But I won't give in, in that way” (Maureen).

All of the participants are living with certainties, which include knowing that their illness will progress further before they die, and uncertainties, which include not knowing how long they have left to live, and how they will die. In the present, they are anticipating their future (see Table 23 below):

TABLE 23 ANTICIPATING THEIR FUTURE

How long have I got?	“The interesting thing is, of course, the stock answer, when people ask how long they’ve got, is three to five years, and I’m never certain whether that three to five years is from diagnosis, or from actual onset of the disease. So just being silly, if you think the first noticeable symptom occurred in October, ’09, I must have had... I must have had the disease prior to that, and... let’s say June, and since that time, as I say, the rate of degradation, or degeneration, has been relentless” (James). “There was a period when I just had a bit of a chest infection, early January, and you start to think oh I can't breathe, this that and the other, and you think I might not be around in three months and you start to panic” (Charles).
How will I die?	“I mean I do try and ask them, er you know, when I am going to die, and is it going to be pneumonia, is it this? And they all seem to be very reluctant to communicate that” (Martin). “When I went back to [name of hospital] and when I was talking to [name of nurse] she said ‘Well I am surprised that you have spoken like this’, things about when you die and all that, because how it comes. She said ‘I am amazed that you have asked these questions’. So you see I am just beginning to open up, my sister was with me” (Maureen).

The one common denominator is that all the participants have been involved with their local MND Care Centre, where the focus of care has been on monitoring and alleviating the

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physical and functional symptoms of MND, and this has also been the focus of the care they have received in the community.

6.11 CONCLUSIONS

Layered interpretations has meant the individual parts of aspects of existence have been understood in light of the whole (Moran, 2000), for each of the participants, and then for shared patterns as a whole. It is understood that interpretation is never complete, and a reader of this thesis with different presuppositions will interpret the texts differently. That said, being there, listening to, understanding and interpreting the individual stories has provided a deeper understanding of what it means to be a person living through the illness trajectory of MND than I had anticipated.

CHAPTER 7 - DISCUSSION OF FINDINGS

7.1 INTRODUCTION

This chapter begins by providing an overview of the background/literature for this study, its purpose and aim. This study brings to the literature an understanding of living with MND beyond the illness context. The findings suggest the four participants involved in this study have experienced “existential loss” of past ways of being-in-the-world, embodiment, spatiality, future. On the basis of these findings, a conceptual framework recommending a lifeworld approach to care as a clinical tool has been developed.

7.2 BACKGROUND/LITERATURE REVIEW

The current evidence in the U.K. has identified that receiving a diagnosis of motor neurone disease (MND) is an “existential shock” (Brown, 2003). Living with MND is a “biographical abruption” to a previously planned life (Locock, Ziebland and Dumelow, 2009). People talk about living with MND as a “fracturing narrative” (Brown and Addington-Hall, 2008). These studies indicate that people living with MND have serious existential concerns. Outside of the U.K. research has focused on the existential concerns of people living with MND (Bolmsjö, 2001). A secondary analysis has found that talking about death and dying remains “taboo” amongst family and health care professionals, as this was linked to hope (Ray, Brown and Street, 2012). Failure to explore existential and spiritual concerns may lead to existential suffering at the end of life (Murata and Morita, 2006).

The purpose of this study was to gain an understanding of living with MND, receiving health care, and the impact on self and identity, in order to contribute to caring policy and practice. The aim was to answer the research question: “What does it mean to be a person living through the illness trajectory of MND?” and to study the phenomenon of existence when given a diagnosis of MND in the context of receiving health care through time. The process of understanding (interpretation) involved looking deeper at the participants’ meaning of existence (ontic and ontological aspects of being) through the three temporal dimensions – past, present and future. This study adds something new to the literature, namely the

understanding (interpretation) that living with MND is experienced as an “existential loss” of past ways of being-in-the-world, loss of embodiment, loss of spatiality, loss of future.

In what follows, an attempt is made to bring together the lifeworld of four participants diagnosed with MND. In some instances typicality can be observed, whilst in others their individual and unique emotional response to MND is evident.

7.3 THE MEANING OF EXISTENCE

“The three tenses of time – past, present and future – are what Heidegger refers to as ecstasies (literally ‘ways in which we stand out’). These ecstasies are absolutely cohesive: to understand any one of these temporal dimensions, in fact, to even consider any one of them, we must appreciate their relation to the others” (Weixel-Dixon and Strasser in van-Deurzen and Arnold-Baker, 2005, p.228).

Heidegger holds that Dasein's being is through time: human beings born into a particular culture may choose to adopt their forebears' ways of being, or project themselves forwards into other possibilities (Inwood, 1997; Moran, 2000). There is a paucity of research considering how MND has impacted on a person's past ways of being-in-the-world. Most of the current available research focuses on the person living with MND in the present tense (Brown and Addington-Hall, 2008; Locock, et al., 2009). Although both the above research studies uncovered existential issues of loss, no study exists that has understood (interpreted) the meaning of existential loss: past ways of being-in-the-world, embodiment, spatiality, future. Inviting the participants to tell their stories from when they first thought there might be something wrong with them, meant they were reflecting back to first noticing changes to their body. For Heidegger, “the body is inconspicuous, though it is there, it lies in the background of all Dasein's doings, not in the foreground” (Inwood, 1997, p.29). The counterargument to Heidegger's statement is that the body is conspicuous, especially when living with MND, because the participants are no longer able to continue with their past ways of being-in-the-world. For people living with MND, there is no choice but to stop doing the activities that gave them meaningful and purposeful identities. Ashworth further emphasises this point: “illness though bodily may well be most felt through the way in which our projects are thwarted” (Ashworth, 2006, p.216). A closer look at the “givens” of existence helps us to understand (interpret) the ontological response to being thrown into the world of MND.

BEING THROWN INTO THE WORLD OF MND

The “givens” of existence Heidegger terms our “thrownness” into the world, into events and conditions we do not choose and cannot control. Thus, we do not choose the place where we are born, our parents, [and] the circumstances of our life (Cohn, 1997, p.126). The participants did not choose to be thrown into the world of MND. They did choose to face up to their conditions and to remain where possible in control of the “givens of existence”. Alternatively they could have denied their conditions, or allowed their circumstances to control them. Allowing their conditions to control them may have resulted in a number of attitudes, such as idealization, resentment, confusion, and a feeling of paralysis (Cohn, 1997). The findings suggest that Martin and Maureen were more positive about living with MND, though they did not consider their life as ideal. James and Charles had developed attitudes of resentment because MND was impacting on their past and future lives. All the participants face their future with uncertainty; they are not confused, but they do live with anxieties. A sense of paralysis is life ruled in the shadow of loss (Cohn, 1997). A sense of paralysis is not to be confused with experiencing paralysis because of the loss of upper and lower motor neurons and its impact on movement. It may be that for James life is ruled in the shadow of loss, and as such he is making resolute choices. These study findings are not unique: Bolmsjö (2001) also identified important ontological aspects of being related to thrownness, a fear of not being in control of current and future lives. Similarly, such fear is reflected in the participants’ stories. The participants’ stories move onto their experienced present (ontic and ontological): embodiment, spatiality, mood and Being-with-others.

LOSS OF EMBODIMENT

Embodiment relates to the physical, psychological, social and spiritual ways of being (Heidegger, 1962; Inwood, 1997). The current available evidence acknowledges the remarkable degree of variance in the presentations of MND (Talbot and Marsden, 2008). The variance is due to the type of MND diagnosed and the progressive nature of each type (MNDA, 2013). The physical symptoms include rapidly progressive muscle weakness (atrophy), fasciculation, muscle spasticity, dysarthria, dysphagia and dyspnoea (Leigh, et al., 2003). The medical view of types of MND and symptoms does not inform us about how the physical symptoms are being experienced. Brown (2003) focused on the impact of MND on the person in their present state: “bodily deterioration coupled with a loss of social and

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communication outlets forces a person to turn inward, to face death in an increasingly difficult day to day life". The participants describe the impact of MND on the embodied self in their spatial world as degrading, humiliating, and cruel because of altered self-image and fear for physical safety. Because there is no existing study that has understood the ontic/ontological aspects of existence with MND, similarities are drawn to Ashworth (2006) here in relation to an existence with Alzheimer's, which is understood by the patient as "embodiment just is". Ashworth goes on to define what he means by this statement: "the body may seem to need no particular protection from the gaze of others and may not be vulnerable to negative assessment – indeed praise about her appearance is not sought" (Ashworth, 2006, p.220). These findings bring together stark differences between two neurological diseases and the experienced impact on the body, without suggesting that any one of these neurological conditions is any more debilitating than the other.

LOSS OF SPATIALITY

If an existence is being-in-the-world, it is "spatial", and as such part of a wider context to which it is related (Heidegger, 1962; Cohn, 1997). In their spatial world, the participants have discussed the need to be with others for their survival. In their spatial world, they have also discussed the need for aids and adaptations for their physical safety. Both are a constant reminder of their loss of control and increased dependency. In their spatial world they have accepted health and social care professionals, not through choice, but for survival. Spatiality is dependency and limited choice. Ashworth (2006) described spatiality for a person living with dementia: "the rescheduling or re-routing of a local bus service, or a change (at the behest of planners and developers) to a familiar place, can shrink the world". The spatial worlds of people living with dementia and those living with MND are not too different. The argument here is that both neurological conditions involve changes to the embodied self, though these changes are notably different in symptoms and effect. Both conditions result in the shrinking of a spatial world. A person living with dementia and a person living with MND has no choice but to accept care if they are to survive in their spatial world. Control has been seen to be an issue for only one of the participants. Maureen had limited control over accepting overnight carers; without accepting them she would not survive in her spatial world. The next part of the discussion on findings involved understanding (interpreting) the participants' mood in relation to their lifeworld.

MOOD

Heidegger (1962) holds that we are always in one mood or another, and that is how we understand ourselves. Two of the participants have said they are not depressed, but sad. People diagnosed with MND have been perceived to be at risk of depression because of the effects of MND on everyday functioning (Hogg, et al., 1994). According to the American Psychological Association (APA) (2014) depression is more than just sadness. People with depression may experience lack of interest and pleasure in daily activities, significant weight loss or gain, insomnia or excessive sleeping, lack of energy, inability to concentrate, feelings of worthlessness or excessive guilt and recurrent thoughts of death or suicide (APA, 2014). The participants have discussed weight loss, insomnia, and lack of energy; though they have not discussed feelings of worthlessness, they have talked about recurrent thoughts of death. Two participants discussed recurrent thoughts of assisted suicide, again not because they are depressed, but because of their emotional response to their existential “given”. The variance in mood/attitude to their existential “given” is evident. Similarly, Brown and Addington-Hall (2008, pp.205-06) captured expressions of distress in their fracturing and enduring narrative, and expressions of finding positive meaning in life in their preserving narrative. The next section on the discussion of findings involved understanding (interpreting) what the health care professionals are doing to help people with their expressions of distress.

BEING-WITH-OTHERS

We have a choice as to whether we are with others or not (Heidegger, 1962; Cohn, 1997). Being diagnosed with MND means people do not have a choice but to be associated with health care professionals for their diagnosis, management of symptoms, and survival. For three of the participants with ALS-type MND the involvement with health care professionals began to intensify in the second year of the illness trajectory, and much later for one participant with PMA-type MND. Brown (2003, p.215) states that the need for “professional and carers to interact with people with MND as ‘being human in extremis’ cannot be overemphasized. Keeping the focus on the person rather than the disease appears so simple, yet so challenging”. Similarly, Bolmsjö (2001, p.504) states that “in the absence of a curative treatment, it is the individual rather than the disease that must be cared for”. The study findings concur with Brown’s (2003) and Bolmsjö’s (2001) by suggesting that from the point of diagnosis the focus of care and treatments is on the person living with MND. The

participants commented on the care they received from the multidisciplinary team at the MNDA Care Centre and in the community, which in the main focuses on the management of their medical and functional needs. The participants' experiences of receiving health care are consistent with the MNDA (2013) practice guidelines. Care that focuses on the medical and functional needs of the person in the present is not focusing on their emotional response to existential loss of past, and is not focusing on their emotional response to existential loss of future. The next section of this discussion on findings concentrates on understanding (interpreting) the participants' emotional response to facing their own mortality.

FACING THEIR OWN MORTALITY

“We are never a ‘finished’ item, or a totalised entity in our lifetime: we are always ahead of ourselves in the process of becoming, until we become no more. We do not make our choices, or choose ourselves, once and for all: we are faced with choosing and re-choosing as we project ourselves towards our deaths. Furthermore, by virtue of the interconnectedness of the ecstasies, every choice impacts on and is affected by, all three dimensions of temporality” (Weixel-Dixon and Strasser in van-Deurzen and Arnold-Baker, 2005, p.229).

For Heidegger, the three dimensions of temporality are expressed as follows: the past is carried along into the present that is always anticipating the future. The process of facing death is filled with anxieties because of certainties and uncertainties. For example, certainties included the knowledge that their illness will progress further before they die, and some of the uncertainties are not knowing how long they have left to live, and how they will die. In the present, they are anticipating their future. McPherson, et al., (2007) found people have a fear of becoming a burden when they are nearing their end of life. Fear of becoming a burden was discussed by one participant, but off tape, and so for confidential reasons this cannot be discussed. Another participant was dealing with his fear of becoming a burden: he had organised some respite care, which involved him going into a hospice to give his wife a break from caring. This same participant discussed being in the process of documenting his needs, priorities and preferences in an advance directive (living will):

“There will come a time when you think I’ve had enough, and, therefore, that will be probably the time to stop feeding, stop this [points to non-invasive breathing machine] and please make me as comfortable as possible in the period whilst I fade away type of thing” (Charles).

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The findings suggest that discussion about end-of-life is being left until people are in the second year of their illness trajectory. A key recommendation of the End-of-Life Care Strategy for England (2008) is for explicit discussion around death if a person is likely to die within 12 months (DH, 2008). The findings may indicate that the timeliness of end-of-life discussion is consistent with practice guidelines. Beauchamp and Childress (2001) advocate the timeliness of the information given in relation to maleficence and beneficence. Maleficence refers to cases in which it is considered harmful to overwhelm the patient with information when they may be unwilling or unable to understand the information. Beneficence refers to actions that should benefit people. There is a fine line to follow in MND between maleficence and beneficence; it is argued that not discussing needs, priorities and preferences early in the illness trajectory may mean people lose their ability to communicate and sign the documentation (Preston, et al., 2012). All of the participants involved in this study are able to understand the information about how their illness trajectory is likely to progress at end-of-life. Providing information on their illness trajectory may outweigh any risk. Although all of the participants can still communicate, three are no longer able to sign this important end-of-life documentation. The findings are suggesting discussions about needs; priorities and preferences are happening too late in the illness trajectory. Doughty (2012) reported on the landmark decision in which a judge at the Court of Protection approved a contested living will. The patient living with MND wished for his ventilation machine to be turned off when he no longer had a quality of life. He had discussed and documented his needs, preferences and priorities in an advance directive (a legally binding document) when he could still communicate and sign the documentation.

Bolmsjö (2001) also identified important ontological aspects of being related to mortality, such as thoughts about death creating anxiety, suicidal thoughts and thoughts of euthanasia. This study brings forward three different opinions on the value of life and views of euthanasia via the Dignitas route: James is determined to act; for Martin it is not an option; and Charles acknowledges that this was once a possible option, at least in the initial stages following diagnosis, though he states:

“But generally if you start looking at other people and think god am I that bad, and if they have symptoms that... obviously they are able to speak which I don't know, for instance, what my attitude would be going back to a will to live, if I lose my speech” (Charles).

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These are powerful words spoken by a man who lives in “hope” to live long enough to see his boys home from university and, in his own words, “to know that we are getting on all right”. The next part of this discussion of findings involves understanding (interpreting) the participant’s loss of temporality and spatiality from an existential therapeutic perspective.

FACING THEIR LOSS OF TEMPORALITY AND SPATIALITY

Medard Boss (1903-1990) was a Swiss psychiatrist who adopted Heidegger’s view on being-in-the-world to inform his own practice (Cohn, 1997). Boss suggests that loss of temporality (past, present and future) and spatiality can result in melancholia⁵ because the experience of loss is not just anticipated, it is a fact (Boss, 1994 in Cohn, 1997). Boss provides reasons for what happens to patients experiencing melancholia: “of the three temporal existential extensions of past, present and future, the first and third are almost totally covered up in such patients, so much so their existence is practically reduced to the present” (Boss, 1994, in Arnold-Baker, 2005, p192). The findings suggest that the participants are experiencing mixed degrees of loss of temporality and spatiality; though they may not be depressed, they may be experiencing melancholia (their emotional response to MND). The following are examples of loss of temporality and spatiality that appear more profound for each participant:

- James talks about his past ways of being-in-the-world of professional sports as loss, his present is likened to being a prisoner on death row, and he can no longer see his future. He has expressions of distress that need acknowledgement and treatment.
- Martin talks about his loss of past ways of being-in-the-world of business, loss of embodiment and spatiality. Despite such losses he is grateful for living on borrowed time and being able to plan for his future. He has made resolute choices not to go into the hospice, but to die at home, or at the office or in the car. He has identified that his wishes, priorities and preferences need to be discussed and documented in an advance directive whilst he can still communicate, though he is no longer able to sign the documentation.

⁵ Melancholia - In a modern context, "melancholy" applies only to the mental or emotional symptoms of depression or despondency; historically, "melancholia" could be physical as well as mental, and melancholic conditions were classified as such by their common cause rather than by their properties (Berrios, 1988).

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- Charles does not focus on his loss of past, or loss of embodiment and spatiality in the present; he is experiencing a loss of once-projected future with his family with incredible sadness. Despite this, he has hope to see his boys home from university and settled. He is in the process of discussing and documenting his end-of-life plans in an advance care plan/advance directive.
- Despite Maureen's loss of past ways of being-in-the-world of retirement, loss of embodiment and spatiality, she remains positive and has recently started discussing her future and has planned her funeral. Although Maureen finds it difficult to talk about her future, her wishes, priorities and preferences need to be discussed and documented in an advance directive whilst she can still communicate, though she is no longer able to sign the documentation.

These study findings bring to the literature an understanding that people living through the illness trajectory of MND do experience existential loss of temporality (past, present and future) and spatiality. At the time of data collection, they did not perceive they were depressed. However, they did have other expressions of distress which needed to be recognised by health care professionals (McLeod and Clarke, 2007).

7.4 A LIFEWORLD APPROACH TO MND

The findings have been conceptualised into a framework, which used as a clinical tool will prompt multidisciplinary health care professionals to focus on the key areas of the patient's lifeworld. The key areas are: 1. lived-through past, experienced present, and anticipated future; 2. their emotional response to the existential "given" of being diagnosed with a life-threatening illness; 3. the meaning of their existence. The application of this lifeworld approach to health care recognises individual and social concepts such as: 1. the individual is recognised as a self-interpreting being with a history, culture and practice; 2. the individual is a self-interpreting being with rights to make choices; 3. recognition of being with others (in their social and cultural world); 4. the individual has freedom and rights: freedom from unwanted medical intervention and rights to stop life-sustaining treatments. The overriding care principle for this lifeworld approach to healthcare is minimising: loss of past ways of being-in-the-world; loss of embodiment; loss of spatiality; loss of future. For recommendations for a lifeworld approach to healthcare, see Table 24 below:

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Lifeworld approach to MND – a clinical tool							
Four key areas of lifeworld	Existential ‘givens’	Meaning of existence	Individual and social concepts	Care principle	Recommendations for Lifeworld approach to health care		
Lived-through past	Loss of past ways of being-in-the-world and being-with-others.	People are involved with things, projects and people that they “care” about.	Individual is a self-interpreting being with a history, culture and practice.	Minimising loss of past ways of being-in-the-world.	Listening to the person’s story of living with their life-threatening illness.	Help the person to acknowledge that their past ways of being-in-the-world have been meaningful and purposeful. Help the person to explore conflicts.	Help the person to explore conflicts in relation to their existential “givens” by referring to an existential counsellor
Experienced present	Loss of embodiment (physical, psychological, social and spiritual ways of being).	People experience illness on their bodies in different ways, such as degrading, humiliating and cruel because of altered self-image and fear for physical safety.	Individual is a self-interpreting being able to make choices.	Minimising loss of embodiment.	Listening to the person’s concerns for their loss of embodiment.	Focus on the themes that may emerge as important to the person. This may not involve a medical and functional approach to care.	

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Experienced present	Loss of spatiality (self in their world as before).	People are part of their wider cultural context, they may experience dependency and limited choice.	Individual is a being-with-others (in their social and cultural world).	Minimising loss of spatiality.	Listening to the person's needs, priorities and preferences whilst recognising they may also be considering the needs of significant others.	The person may wish to make what are considered unwise decisions, refer to the Mental Capacity Act (2005) best interest checklist (DCA, 2007a).
Anticipated Future	Loss of a once projected future anticipating certainties of being-towards-dying, and uncertainties of when and how they will die.	People anticipate their future because of their lived-through past, and experienced present.	Individual has freedom and rights: freedom from unwanted medical intervention and rights to stop life-sustaining treatments.	Minimising loss of future.	Listening to their existential concerns for the future, facilitate information giving if patient has a willingness to interpret choices and the ability to make rational decisions.	Help the person to discuss their existential concerns, and to document their needs, priorities and preferences for end-of-life care in an advance care plan/advance directive.

A further explanation of the lifeworld approach and how this may potentially be utilised as a clinical tool in health care practice is given here. The three key areas of existence serve as a dialectic approach to enable the person diagnosed with MND to reclaim the meaning of their life as lived, as experienced, and as anticipated. The purpose of this dialectic approach is to guide multidisciplinary health care professionals on the key area(s) of existence that are important to the patient. The process involves enabling the person to come to terms with the inherent contradictions of human living, and allowing them to reclaim personal freedom (van-Deurzen and Arnold Baker, 2005) and direction of their health care. The lifeworld approach used as a clinical tool for people diagnosed with MND may also be used as a clinical tool for people diagnosed with other life-limiting illnesses. The timing of this study is appropriate, as a review into end of life care services in England has been launched. Henry (2014, p.8) states: “we only have one chance to get it right for people who are dying, but despite some excellent practice many people are not currently getting the care and support that is right for them”. Freedom to make choices is the key message of the lifeworld approach as a clinical tool.

7.5 CONCLUSIONS

The purpose of this study was to gain an understanding of living with MND, receiving health care, and the impact on self and identity, in order to contribute to caring policy and practice. The aim was to answer the research question: “What does it mean to be a person living through the illness trajectory of MND?” and to study the phenomenon of existence when given a diagnosis of MND in the context of receiving health care through time. Three of the participants involved in this study were in the second year of their illness trajectory, and one of the participants had been living with MND for 10 years. At the time of data collection, the participants may or may not have been nearing their end of life. The findings suggest that the participants are experiencing varying degrees of existential loss, described from these findings as loss of past ways of being-in-the-world, loss of embodiment, loss of spatiality, loss of future. The focus of health care has been on their medical and functional needs, and not on the participants’ existential loss and concerns. Three of the four participants were referred into the hospice services, which may indicate they were in the last year of their illness trajectory. The findings suggest that despite experiences of existential loss and concerns, none of the participants report having experienced depression through their illness trajectory,

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though two of them described feelings of sadness for their loss of future. All of the participants were experiencing existential concerns for their future because of certainties that their illness will progress, and uncertainties of when they will die, and how they will die. These are expressions of distress that need to be recognised by health care professionals. These findings are similar to Brown and Addington-Hall's (2008), who emphasise the importance of health care professionals listening and understanding people's distress. The findings in this study may suggest that those people experiencing existential loss are at risk of existential suffering as they near their end-of-life, if their loss is not explored throughout their illness trajectory, and whilst they are still able to communicate. The central argument from these findings is that a lifeworld approach to care for people living with MND may prevent people from experiencing existential suffering at their end-of-life.

CHAPTER 8 – REFLEXIVITY

8.1 INTRODUCTION

This reflexivity chapter is divided into three sections. The first one deals with the nature of my reality in my experience of doing a Master of Philosophy and the challenges it entailed. The second focuses on the relationship between the researcher and the participants involved using a reflexive diary to aid the process of being open to the meaning of another. The third considers the question of how we know the world or gain knowledge of it in the process of becoming a hermeneutic phenomenologist.

8.2 ONTOLOGICAL REFLEXIVITY

EXPERIENCING AND DOING

Experiences of supporting my mother in living with MND meant that I came to this study to interpret the meaning of others. As an interpretive researcher, I understand that the basis for explaining social life and social events and for understanding people is not “science” in the positivist sense but in the common sense, for it contains the meaning people use to make sense of their life. I was questioned from the outset about whether I could remain objective throughout my study. The question was posed by a positivist researcher who understands that science is based on strict rules and procedures (Sarantakos, 1998). In response to the sceptic who questioned my ability to bring something new to the existing evidence because I am locked into my particular presuppositions (history, beliefs, prejudices and pre-understandings), I argue:

Interpretation is never a presupposition-less apprehending of something presented to us. In every case this interpretation is grounded in something (Heidegger, 1962, p.123).

My efforts to address my presuppositions were to bring the experiences of supporting my mother living with PBP MND to consciousness before starting the study. In doing so, I sought to understand the meaning of existence for others diagnosed with MND.

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The research involved having an idea because of my experiences and the examination of the existing literature in MND. The purpose of this study was to gain an understanding of living with MND, of receiving health care and of the impacts on self and identity, in order to contribute to caring policy and practice. The aim was to answer the research question: “What does it mean to be a person living through the illness trajectory of MND?” and to study the phenomenon of existence when given a diagnosis of MND in the context of receiving health care through time. Heidegger asked the ontological question: “What does it mean to be a person?” because he was interested in the meaning of existence through time (being and time) (Heidegger, 1962). Gadamer’s hermeneutics involved being open to the meaning of another (Gadamer, 1975). Throughout the stages of interpretation I have attempted to remain as aware as possible of the existential hermeneutic phenomenon (via the participant story) and the self (via the research journal). In doing so, my stance has involved being empathetic and genuinely curious about the meaning of existence for the participants, whilst also being reflexively and critically self-aware of my own presuppositions (Finlay, 2011).

8.3 EPISTEMOLOGICAL REFLEXIVITY

BEING OPEN TO THE MEANING OF OTHERS

“The truth of experience always implies an orientation toward new experience. That is why a person who is called experienced has become so not only through experiences but is also open to new experiences” (Gadamer, 1975, p.355).

At the commencement of this study, I had experiences of working in the community as an occupational therapist with patients with all types of neurological conditions, including MND. In addition, I had experiences of supporting my mother through her illness trajectory of MND. There are lessons to be learnt from experience, and those that I felt important were documented in a reflexive chapter before the start of the study. From completing this chapter I was able to identify the questions which I considered important for the future of others living with MND. A reflexive diary was kept during the study, and I have documented my reflections under the following five headings: 1. meaning of existence; 2. embodied knowing; 3. planning for the future; 4. ethical concerns; 5. focus of care. Each reflection is about using my pre-understanding to develop my interpretation of the meaning of others:

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1. Meaning of existence for others

I came to this study without claiming to have understood what it means to be a person living through the trajectory of MND, because I have not been diagnosed with MND. But I did claim to have an understanding of how MND can separate our bodies from who we are and what we do in the world. Such separation involved the observation of the impact of PBP MND on my mother resulting in a loss of speech before diagnosis, loss of ability to swallow, and loss of movement within 3 months following diagnosis. Such separation is most likely when the person diagnosed with MND is only seen as a person with MND in the present, and not as a person with a past and a future. I chose an approach that focused on the meaning of existence through time. I have understood (interpreted) through this chosen approach that the participants involved in this study are experiencing MND as existential loss of past ways of being-in-the-world; loss of embodiment, loss of spatiality, and loss of future.

2. Embodied knowing

My mother did not ask about her prognosis: she was told at her initial consultation that her PBP MND was rapidly progressive, and she was asked to consider having a PEG fitted. As a daughter I wanted to keep her hope alive, and so I was grateful when health care professionals did not discuss the progressive nature of PBP MND. As a health care professional I understood that she was making the choice to have the PEG with limited information. I come to this study wondering whether others know how their MND will progress, which would enable them to make informed choices about whether to have life-sustaining treatments or not. I now understand that each person diagnosed with MND already has an altered experience of their whole body: they may have lost movement in their arm and consequently have an altered experience of the world because they are no longer able to draw for a living. These are one and the same, because MND impacts on the body and their past ways of being-in-the-world. I have understood (interpreted) that the participants involved in this study may not need to ask how their illness will progress, because they have embodied knowing.

3. Planning for the future

My mother made a decision as soon as she was diagnosed to give me and my brother power of attorney for her financial and medical affairs. What she was not approached to do was complete an advance care plan or an advance directive, so many of the decisions in the care context were left for me and my brother to make. We ensured that she was party to all of the

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decisions although she could no longer communicate verbally – she nodded for “yes” and shook her head for “no”. I came to this study asking whether other people get the opportunity to discuss and document their needs, priorities and preferences for the end of their lives early in their illness trajectory. I observed that one of the participants is at risk of losing his speech - he is already slurring his words - yet he did not mention having had the opportunity to discuss and document his needs, priorities and preferences in an advance care plan and an advance directive; however, he did speak off tape about the fact that he had made his future wishes known to his consultant. I now understand that each person has their own unique emotional response to their future. I have understood (interpreted) that the participants involved in this study have not discussed their needs, preferences and priorities for end-of-life care until their second year of illness trajectory.

4. Ethical concerns

I experienced ethical concerns in the care context, because I understood palliative and end-of-life care values. The ethical concerns were around life-sustaining treatments against my mother’s wishes. I expressed my concerns throughout the end-of-life trajectory but could do nothing about this, or so I was told, because nothing had been documented in an advance directive. Had my mother documented in an advance directive as follows: “when I no longer have a quality of life, please stop nutrition, hydration and all life-sustaining treatments”, this would hold in a court of law. I come to this study wondering whether other people get the opportunity to discuss and document their needs, priorities and preferences for life-sustaining treatments when they are nearing their end of life. Through the literature I understand that a person has a legal right to refuse life-sustaining treatments, so long as they are documented in an advance directive. I have understood (interpreted) that only one participant was in the process of documenting his wishes to stop life-sustaining treatments in an advance directive.

5. Focus of care

Despite my mother being assessed for continuing health care, the focus of care provided by agency nurses was curative and not palliative. I came to this study questioning what the experienced focus of care is for others diagnosed with MND. I understand (interpret) the participants have needs for palliative care because they have existential loss and concerns, but I understand (interpret) that their care is focused on their medical and functional needs. Three of the four participants were in the second year of their illness trajectory when they were

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referred into the hospice services. The World Health Organisation (2002) calls for care that affirms life and death as a normal process (WHO, 2002). The participants are not having the opportunity to do either until the second year of their illness trajectory, by which time they are at risk of losing their ability to communicate.

In summary, my presuppositions were brought into the hermeneutic circle to understand the meaning of another; these developed interpretations are summarised in the following ways (see Table 28):

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TABLE 28 DEVELOPED INTERPRETATION

Presuppositions	Understanding the meaning of another	Developed interpretations
I came to this study understanding that MND can separate our bodies from who we are and what we do in the world.	Meaning of existence	I have understood (interpreted) through this chosen approach that the participants involved in this study are experiencing MND as existential loss of past ways of being-in-the-world; loss of embodiment; loss of spatiality; and loss of future.
I came to this study understanding life-sustaining decisions were made with limited information on prognosis.	Embodied knowing	I have understood (interpreted) that the participants involved in this study may not need to ask how their illness will progress, because they have embodied knowing.
I came to this study understanding discussions about needs, preferences and priorities for end-of-life care are not being discussed early into the illness trajectory.	Planning for the future	I have understood (interpreted) that the participants involved in this study have not discussed their needs, preferences and priorities for end-of-life care until their second year of illness trajectory.
I came to this study understanding that discussions about life-sustaining treatments when a person is nearing their end of life are not being held early into the illness trajectory.	Ethical concerns	I have understood (interpreted) that only one participant was in the process of documenting his wishes to stop life-sustaining treatments in an advance directive.
I came to this study understanding that the focus of care received was aimed at the person with MND.	Focus of care	I have understood (interpreted) that the participants involved in this study have received care that is focused on their medical and functional needs.

8.4 METHODOLOGICAL REFLEXIVITY

BECOMING A HERMENEUTIC PHENOMENOLOGIST

“Hermeneutic phenomenology sets out to describe human beings as they show up in ‘average everydayness’, prior to high-level theorizing and reflection. From this standpoint, human existence is found to be meaning- and value-laden, and so in need of interpretation in order to be properly understood. The description of everydayness leads to a critique of the ‘substance ontology’ presupposed by many natural sciences, and instead characterizes a human being as an ‘event’ or ‘life story’ unfolding between birth and death” (Guignon, 2012, p.97).

I understood that by using a life story method, people may omit stories that are too painful for them to recall. The participants recalled events from when they first noticed something untoward was happening to them, and included stories of being diagnosed, of the initial months, of getting on with life as before, of the experienced present, of coping and not coping and of making plans for the future. I was not prepared for such articulated, in-depth detail. The participants understood that I had arranged support systems should they need to talk to someone after the interview. None of the participants asked to be referred to the support systems. The life story approach used for this study enabled the participants to locate their voices in their stories, to reflect on their past ways of being in the world, on their experienced present, their once projected future and their plans for the future. Some of the participants needed a conversational approach to enhance their story, depending on whether they were natural storytellers.

In the research setting, I was able to build on my observation skills, which are central to the practice of occupational therapy. This also proved a challenge, because as a therapist I observed the need for resting splints for two of the participants, as their arms were oedematous and hung heavy at their sides. Another participant was almost doubled over because of her loss of upper body control, and was at risk of falls in her home environment. Carrying out the interview with the participants in their own homes, I observed that the occupational therapist had been involved in their care. On one occasion the interview process was disrupted by the district nurse visiting to attend to one of the participants’ injuries following a fall. On arrival to interview at one participant’s place of work, I noted that he was still ambulant and able to climb the stairs to his office. One participant invited me to have a coffee, and I noted his loss of upper body movement impacting on his ability to retrieve milk from the fridge. I understand through these

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observations that these people are heavily involved with a number of health and social care professionals in the community. I also understand that another researcher from a different professional background may not have taken all of this in. The opposing view is that a researcher from another professional experience could have picked up on other things. Although I make these observations, my approach to data collection allows the participant to talk about themselves in their lifeworld.

The competing challenge of being a therapist-researcher is considered in the following ways: as a therapist I had observed two people in need of resting splints and in need of a falls assessment; as a researcher I am unable to refer them to the services that would be able to meet these needs. As a therapist I have to disclose to significant other(s) when a person discusses their intent to do harm to self or others (COT, 2010). As a researcher, having to add this statement to my consent form may have left the participants feeling unable to disclose their thoughts on harm to self/assisted suicide, knowing that their interview was being recorded. As a therapist I gather information on living with disability/illness/life-threatening illness, I understand (interpret) from a holistic view the impact of their illness on their physical/psychological/social/spiritual self. As a researcher I gather stories on the meaning of existence through the illness trajectory, I understand (interpret) from an existential perspective the impact of MND on their lifeworld through time. The challenge for me as a therapist-researcher is to bring the existential perspective to the existing evidence, in order to contribute to caring policy and practice.

Hermeneutic (interpretive) phenomenology has helped me to unfold my presuppositions into developed interpretations (Polt, 1999). I had not anticipated how having a phenomenological attitude would deepen my understanding of the impact of MND on a person in their lifeworld. For example, a participant living with MND for 2 years said: "I was left handed, whereas now I am not any handed of course, but I was left handed".

When Martin speaks of this loss of movement in his hands, it is more poignant because he used draw for a living. Understanding the participants in their lifeworld provided a deeper understanding of what it means to be a person living through the trajectory of MND.

Hermeneutic (interpretive) phenomenologists emphasise their findings in a way that evokes lived experience (Finlay, 2011). The poem I wrote directs the gaze towards where meaning originates, that is, with the person who has lived through the past, an experienced present and an anticipated future:

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There is more to me than MND

I am a person with a past

I am a person with a present

I am a person with a future

I am a person with a past way of being-in-the-world

I have lived a fulfilling life

Are you interested in my story?

I am a person who just happens to have been diagnosed with MND

I have a voice, I anticipate my future

Will somebody listen to my concerns?

I am a person who once had a future filled with hopes and dreams

I still have a future with a bucket load of wishes before I die

Will somebody listen to my wishes?

I am a person who lives with uncertainty

But I am certain that my life has been meaningful and purposeful

Because you listened to my story

-Denise A. Harris, 10.09.13

8.5 CONCLUSION

In this chapter, I have reflected upon how the hermeneutic phenomenological approach chosen for this study has provided a depth and richness to understanding the particular ways in which a person is in the world and their emotional response to MND. In addition, as a researcher I have been open to a new understanding while remaining faithful to my starting point, my inherited outlook and my presuppositions (Heidegger, 1962, Gadamer, 1975, Moran, 2000). This lifeworld approach has provided an opportunity to bring forward people's lived experiences. In doing so, the participants have helped to answer the questions that brought me to this study:

1. What is the meaning of existence for others when given a diagnosis of MND?
2. What are other people's existential concerns?
3. Do other people get a chance to affirm life and death as a normal process?
4. Do other people get the opportunity to discuss and document their wishes and preferences for their end of life?
5. What is the experienced focus of health care for others diagnosed with MND?

The next chapter will discuss the findings in relation to the research contributions, research implications for practice, and critical evaluation of the research (strengths and weaknesses). It will then move on to discuss what could be done differently, and what has been learnt about the topic, research and education.

CHAPTER 9 - CONCLUSION

9.1 INTRODUCTION

The database on how people are living with MND is growing, and with the availability of the World Wide Web stories of individuals living with MND are becoming more readily accessible. Patients have their own individual unique way of living with MND, and health care professionals need to understand how best to manage this individual uniqueness. The four participants involved in this study are experiencing varying degrees of existential loss before their terminal stage of disease, defined from the findings as loss of past ways of being-in-the-world; loss of embodiment; loss of spatiality; loss of future. The recommendations from this study are for health care professionals to pay closer attention to the meaning of MND on a person's lifeworld (past, present and future). The findings have been conceptualised into a framework, which used as a clinical tool will prompt health care professionals to focus on their patient's existential loss and concerns. This clinical tool has been developed through the philosophy behind this study, which suggests we are all temporal beings-in-the-world (Heidegger, 1929/1962). As Widdershoven (1993, in Atkinson, 1998) suggests, we live our life in stories: the stories we tell are important for our identity, as they tell us who we are. Through the telling of their stories the people involved in this study have created their identity, enabling the findings from this research project to be grounded in their reality.

9.2 RESEARCH CONTRIBUTIONS

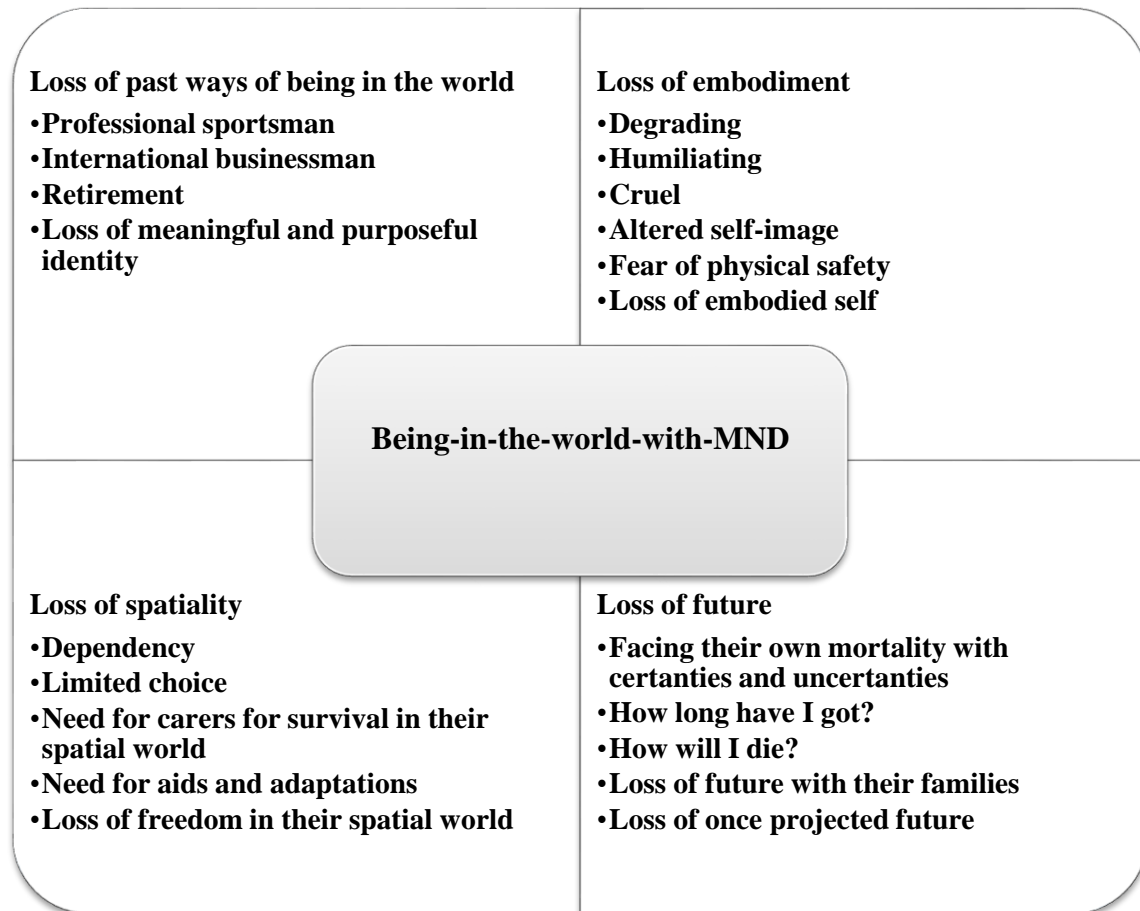
“The qualitative researcher who wishes to get qualitative research out of the doldrums must insist that it is not sufficient to define their work in terms of technique (the use of qualitative data or a qualitative approach to analysis); nor should they be stuck at the level of theory or method (where a researcher might say, I am following the procedures of symbolic interactionism, or discourse analysis, or phenomenological human science), but that they should always have regard for the methodological level, the paradigmatic level, the level of awareness of epistemology and ontology” (Ashworth, 2006, p.212).

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As recommended by Ashworth (2006), this research study began with some basic understanding of ontology (what is the nature of reality). As a qualitative researcher, I did not come to this study with embodied knowing: what it is like to be given a diagnosis of MND, and to have your once projected future cut short by a life-threatening disease. I do not have experience of what it is like to live each day waking up to the loss of use of another part of your body, and to have to give up your past ways of being-in-the-world. Or experience of what it is like to have your spatial world diminish.

Embodied knowing, namely what it means to be a person living through the illness trajectory of MND, was not evident through the existing literature. This study asked four participants to tell their story of the existential phenomenon of living through the illness trajectory of MND. The individual stories include experiences of when they first noticed something untoward was happening to them, being diagnosed, continuing with life's projects, MND impacting on their past ways of being-in-the-world, MND impacting on their embodied self, MND impacting on their spatial world, MND impacting on their once projected future. The individual stories included existential concerns for their future and for those they leave behind. The participants' stories have taken the meaning of existence with MND to a deeper level, as emphasised in Table 30 below:

FIGURE 2 BEING-IN-THE-WORLD-WITH MND IS:



9.3 RESEARCH IMPLICATIONS FOR PRACTICE

The MNDA (2013) care pathway recommends healthcare professionals focus their assessments on the loss of function: use of arms, ability to walk, ability to manage personal hygiene and care, speech, ability to swallow, respiratory function and cognitive function. It is only when a person experiences a loss of speech and respiratory function, or is considered to be nearing their death, that referral to the palliative care team is recommended (MNDA, 2013). Similarly, occupational therapy practice guidelines also suggest a functional approach:

OTs play a vital role in supporting individuals with MND and their families at all stages of the illness. With progressive wasting of muscles and increasing weakness in limbs, this has a significant impact on an individual's function and ability to carry out their daily activities. The presentation and progression of symptoms are different with each person. Because of these differences healthcare requires a flexible, needs led service provided by the OT and the rest of the multidisciplinary team (Fitzsimmons and Arnott, 2012, p.40).

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The MNDA (2013) now directs people with psychological and social issues to the palliative care professionals. This is in sharp contrast to the MNDA (2004) standards of care guidelines that acknowledge the psychological and social issues relating to the loss of role and status in the family and society. The MNDA (2004) standards of care guidelines recommend allowing time to talk about the impact of the illness, allowing time to express and explore feelings, giving reassurance about the normality of the intensity of feelings and conflicting emotions where appropriate, and the acknowledgement that solutions to problems may not exist. The findings from this study identified that the participants were experiencing existential loss at the time of diagnosis. They were not referred into the palliative care services until the second year of diagnosis. This study adds to the literature which has acknowledged that the focus of health care is on a person's functional loss (Brown, 2003; Hughes, et al., 2005; van Teijlingen, 2001). Taking a functional approach to care is not responding to the person's emotional response to MND, which raises concerns about their psychological needs not being met.

As discussed, the participants involved in this study have varied emotional responses to MND, not just because of their loss of embodiment, but because loss of embodiment has impacted on their past ways of being-in-the-world, their spatiality, and their once-projected future. The priorities for two of the participants may have been planning for the future of those they leave behind, ahead of focusing on themselves in the present. All of the participants in this study were able to communicate and could explore their emotional responses to MND with those who were prepared to listen. Some people may lose their ability to communicate early into their illness trajectory, and consequently lose the opportunity to communicate their existential loss and existential concerns. The findings from this study suggest that people need more than a person-centred (DH, 2005) and functional approach to care (Fitzsimmons and Arnott, 2012; MNDA, 2013). A person-centred approach and functional approach to care focus on the person living with MND in the present, and not the person with a lived-through past and an anticipated future.

At the recent International Symposium for ALS/MND, Oliver (2013) emphasised the need for people to prepare for their end-of-life care early into the illness trajectory of MND. Oliver discussed the barriers to end-of-life discussion as follows: 1. a person living with MND may have a fear of the disease progression, and have concerns for the family/carers; 2. a person's

family may fear the unknown, they may not want to upset the patient, and they may fear that the discussion of dying with the patient will reduce hope and affect the disease progression; 3. the health care professionals may fear the patient will become upset, and they have an awareness that not all families want these discussions because of concerns that the patient may give up hope, and because they find it too hard to talk about these issues (Oliver, in Hardiman, 2013, p.20). The findings from this study showed that, of the four participants, only Charles discussed being in the process of preparing for his end of life by having conversations with health care professionals and documenting his needs, priorities, and preferences in an advance care plan/advance directive. This is not to say that the other three participants had not already done so or were not in the process of doing so, but that they did not discuss making such plans whilst they can still communicate. This does confirm that the MNDA (2013) care principles are being followed by health care professionals, because Charles and Maureen, who have a loss of respiratory function, were referred to the hospice services. Although all of the participants involved in this study are still able to communicate their needs, priorities and preferences, three of the four participants are no longer able to sign documents. Consequently, end-of-life documentation may have to be presented later in their illness trajectory in the court of protection.

9.4 LIFEWORLD APPROACH TO CARE

The findings are clearly saying that people diagnosed with MND need support with four key areas of existential loss: loss of past ways of being-in-the-world, loss of embodiment, loss of spatiality, loss of future. The findings of this study are clearly highlighting a need for a lifeworld approach to care in order to help people cope with their unique emotional response to MND.

A lifeworld approach to care acknowledges that there is more to a person than their disease, because the person has a lived-through past, an experienced present and an anticipated future. This study shows that existential loss and existential concerns to be prioritised from the time of diagnosis and monitored throughout the illness trajectory. The participants involved in this study who expressed their existential loss and concerns have been referred onto the hospice services, which in the U.K. remain primarily charitable organisations, with minimal funding from the NHS in the U.K. What the findings suggest is that, without their local hospice

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services, James would not be involved with a counsellor who understood what it means to be a person experiencing a loss of past ways of being-in-the-world, not wishing to face his finitude being unable to move and communicate. Martin would not have his pain managed by the hospice consultant. Charles would not have been discussing and documenting his needs, priorities and preferences for his end-of- life care in an advance care plan and advance directive. Maureen would not have been discussing wishes and preferences for her funeral.

The findings have been conceptualised into a framework which acknowledges personal and social concepts: a person is a self-interpreting being-in-the-world, being-with-others, and being-towards-death. The framework has arisen because of addressing the existential thought (Heidegger, 1962), and interpreted by authors (Ashworth, 2006; Boss, 1994; Binswanger, 1962, Cohn, 1997, Finlay, 2011; Moran, 2000, Polt, 1999, van-Deurzen and Arnold-Baker, 2005).

9.5 CRITICAL EVALUATION OF THE RESEARCH – STRENGTHS AND WEAKNESSES

RIGOUR

The research has been competently managed and worked through the following different stages: from the proposal to gaining ethical approval, completing the necessary training to carry out life story interviews, to gathering, interpreting and disseminating data. In addition, the research is coherent with the background philosophy of hermeneutic phenomenology, exemplified in the method of data collection and of hermeneutic analysis. A systematic approach to the method of data collection and the method of interpretation is documented and could be followed by another researcher. A different researcher, because of their history, culture and practice would interpret the stories differently. The findings of this study do not necessarily match the current available evidence, but they do bring something new to the existing available evidence on living with MND, receiving health care, and the impact on self and identity. An understanding of the stories was verified with the participants at the start of interview 2. The knowledge claims have been validated in dialogue with the study supervisors.

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RELEVANCE

The research study findings, based on a philosophical framework which includes ontic and ontological aspects of existence, add to the body of knowledge. This framework helped to interpret the person in their lifeworld. The research participants were not asked whether taking part in this study was empowering. This study has given each participant a voice and conceptualised their “existential loss”. A clinical tool offers health care professionals guidance on ways to improve the care and treatment of those people diagnosed with MND, or indeed any other life-threatening illness.

RESONANCE

The participant stories were touching because of their willingness to share their unique and poignant account of their illness journey. The excerpts have been used to draw the readers into the everyday lived experiences. The research accounts may impact on the readers’ emotions depending on their own background experiences. The findings from this study have been textured (4 stages of hermeneutic analysis), which has meant gaining a deeper understanding (interpretation) of the participants in their lifeworld. Health care professionals may find that the findings resonate with their experiences of providing care and treatment for people with MND, though the findings also bring new understandings. Adding layers of interpretation means that the findings stay close to the participants’ lifeworld experiences.

REFLEXIVITY

I came to this study with my own history, culture and practice, in addition to presuppositions (pre-understandings, beliefs, and prejudices). In view of my history, I was questioned at the start of the study whether I could remain objective. Therefore, hermeneutic phenomenology was chosen as methodology. Hermeneutic phenomenologists say researchers can never be impartial and objective. Instead, the researcher brings to the task of interpreting the lived experience of others their own history and presuppositions (Finlay, 2011). Presuppositions for this study have included knowledge of occupational therapy as well as knowledge of hermeneutic phenomenology (Heidegger, 1962; Gadamer, 1975). Personal experiences of supporting my mother living through her illness trajectory were brought to the forefront at the start of the study to reflect on aspects of experience that remained important. The study was conceptualised based on those experiences. A reflective chapter explores how my own presuppositions might have impaired (as well as enhanced) my ability to hear and interpret the stories. Ethical integrity was demonstrated by ensuring that those people being invited to take

part in this study were fully informed of what being involved in the research meant for them, and process consent was carried out throughout the interview(s). In addition, the participants were shown respect and empathy by being invited to tell their story, which gave them the opportunity to have a voice; this also overcame the question of power relationships. Those participants not wishing to continue with the research were given the opportunity to withdraw. The study limitations are now discussed.

9.6 STUDY LIMITATIONS

A limitation of this study is the inability to take the findings back to the participants for their thoughts on the researcher's interpretations. I have learnt that three of the participants had died before the completion of the interpretations. I do not claim that all people living with MND will experience existential loss, or that all people are not in receipt of health care that takes account of their loss of past ways of being-in-the-world, loss of embodiment, loss of spatiality, and loss of future. These findings are taken from a small sample of four people. A story approach requires time for attention to detail (Brown and Addington-Hall, 2008). This study did take time to examine the differences between the four presentations of MND and the different stages of their illness trajectory. Although this has taken extra time to describe and interpret, such level of information does add to the current body of knowledge. Interpreting the individual participant stories at a phenomenological level involves iterative listening. Iterative listening was emotionally draining, but deep respect was given to the in-depth stories recounted, and it was considered worthy of the time and emotion to get the participants' stories understood at a phenomenological level. The participants came to this study wanting to make a difference for other people diagnosed with MND. They told their stories, and I listened and interpreted them to understand the meaning of their existence; I took their stories to a deeper level than I had anticipated. Some may argue that using Heidegger's ontic and ontological aspects of existence to interpret the participants' stories may overly structure and constrain the analysis (Finlay, 2011). In response to such arguments, I would state that there is no existing evidence that has focused on both the ontic and ontological aspects of existence when diagnosed with MND.

9.7 WHAT COULD BE DONE DIFFERENTLY

A different existential thought could have been used to frame this study, such as Merleau-Ponty's meaning of existential phenomenology, who emphasised the body as the primary site for knowing the world. He maintained that the body and that which it perceives could not be "disentangled" from each other. However, Merleau-Ponty's thought was rejected because the focus on the body is inappropriate for people with a progressive deterioration of motor neurons now controlling their lifeworld.

A different approach to data collection would be to carry out semi-structured interviews using an interview guide. Semi-structured interviews using an interview guide may have focused on existential issues: the present situation, the future, meaning, guilt, respect, information, confidence (Bolmsjö, 2001). However, this approach to data collection may lead the participant into topics of discussion, rather than giving them the opportunity to reflect on the meaning of existence through their illness trajectory.

A different approach to analysing the interviews would be to focus on the form and content of the patients' narratives; this approach uncovered four narrative types or storylines: sustaining, enduring, preserving, and fracturing (Brown and Addington-Hall, 2008). However, this approach to data analysis does not bring an understanding of the differences in MND, such as the four types and stages of symptom presentations (Brown and Addington-Hall, 2008).

9.8 WHAT HAS BEEN LEARNT ABOUT THE TOPIC, RESEARCH AND EDUCATION

There is an abundance of information on the course of MND and the biomedical management. Evidence of the meaning of existence with MND is sparse. There is a need to develop management approaches of MND that understand the individual has an existential past, an experienced present and anticipated future. The quality of any hermeneutic (interpretive) phenomenological study is its ability to interpret the lifeworld of the participant, and to draw the reader into that world (Finlay, 2006). The hermeneutic mode of understanding the stories has gone deeper than the participants' own understanding (Crotty, 1998). This study adds to the empirical evidence because it brings forward an understanding of what it means to be a person living through the illness trajectory of MND. The contribution this study makes is summarised as follows:

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1. A lifeworld perspective helped to make sense of the meaning of existence when given a terminal diagnosis of MND.
2. The concepts of existential loss identified in relation to MND were loss of past ways of being-in-the-world; loss of embodiment; loss of spatiality; loss of future.
3. The concepts of existential loss require closer attention by health care professionals from the time of diagnosis and through the illness trajectory.
4. The findings have been conceptualised into a framework, which used as a clinical tool will prompt health care professionals to focus on their patient's existential loss and existential concerns.
5. This study adds to the existing literature that is calling for a lifeworld approach to health care.
6. This study adds to the existing body of literature to enhance the education of health care professionals.

9.9 CONCLUSION

The purpose of this study was to gain an understanding of living with MND, receiving health care and the impact on self and identity, in order to contribute to caring policy and practice. The aim was to answer the research question: "What does it mean to be a person living through the illness trajectory of MND?" and to study the phenomenon of existence when given a diagnosis of MND in the context of receiving health care through time. The four participants have provided eloquent stories of their unique existence from the time they first noticed something untoward was happening to them. They have helped us to understand that the focus of the management of MND is medical and functional. Only when healthcare professionals consider that the patient is in their last year of their illness trajectory, or are experiencing respiratory loss, do they refer them to the hospice services for palliative care. This study has uncovered some important issues in relation to people having the right to discuss and document in a "Living Will" their needs, preferences and priorities whilst they can still communicate and sign the documentation. The participants are experiencing existential loss: loss of past ways of being-in-the-world, loss of embodiment, loss of spatiality, loss of future. Despite experiencing existential loss, the four participants were not given the opportunity to explore their loss until the second year of their illness trajectory.

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They were then referred into the hospice service for palliative care. Though none of the participants reported being depressed, two stated they were sad. One participant may be ruled by the shadow of his loss: past ways of being-in-the-world of sports and loss of future with his family; in the present he is making resolute choices. He did independently seek counselling from the hospice services. The findings from this study do help us to make sense of what it means to be a person living through the illness trajectory of MND. The findings are conceptualised into a framework, which used as a clinical tool will prompt health care professionals to focus on the four key areas of existential loss: loss of past ways of being-in-the-world, loss of embodiment, loss of spatiality, loss of future and their emotional response to the existential 'given'.

APPENDIX A: ETHICAL APPROVAL

**Dr John Ealing BSc (Hons),
MBBS, MRCP, DPhil,
CSST in Neurology
Consultant Neurologist**

PRIVATE & CONFIDENTIAL

Denise Harris
398 Holcombe Road
Greenmount
Bury
BL8 4HF

Dear Sir or Madam:

Denise and I met up on the 6th July 2011 to discuss her planned project exploring the impact on self-identity of a diagnosis of motor neurone disease.

Looking at the summary I think this is a very worthy project and assuming all the ethical and R&D documentation is satisfactorily completed I would have no objection what so ever of patients Being recruited from the MND Care Centre here in Manchester.

I would be very keen to see the results in the hope we can improve patient care at the care centre.

Yours sincerely

Dr John Ealing
Consultant Neurologist

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Academic Audit and Governance Committee

Research Ethics Panel
(REP)

To Denise Harris
cc: Dr Jackie Taylor, Ms Sue Braid
From Jayne Hunter, Contracts Administrator
Date 22nd August 2011



MEMORANDUM

Subject: Approval of your Project by REP
Project Title: An exploration of living with motor neurone disease, receiving health care, and the impact on self and identity.
REP Reference: REP11/125

Following your responses to the Panel's queries, based on the information you provided, I can confirm that they have no objections on ethical grounds to your project. However, it has been suggested by the Panel that you establish whether there is a suitable support group participants could be referred to (if not routinely done as part of the treatment pathway), especially if they find discussion unsettling.

If there are any changes to the project and/or its methodology, please inform the Panel as soon as possible.

Regards,

Jayne Hunter
Contracts Administrator

For enquiries please contact
Jayne Hunter
Contracts Administrator
Contracts Office
Enterprise Division
Faraday House
Telephone: 0161 295 3530 Facsimile: 0161 295 5494
E-mail: j.hunter@salford.ac.uk

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Health Research Authority

NRES Committee East of England - Norfolk

Victoria House
Capital Park
Fulbourn
Cambridge
CB21 5XB

Tel: 01223 596906

30 July 2012

Mrs Denise Andrea Harris
D.A.Harris@edu.salford.ac.uk
Graduate Teaching Assistant/PhD student in Occupational Therapy
The University of Salford
Allerton Buildings
School of Health, Sport and Rehabilitation Sciences
Frederick Road Campus, Salford
M6 6PU

Dear Mrs Harris

Study title:	An exploration of living with motor neurone disease, receiving health care, and the impact on self and identity.
REC reference:	11/EE/0364
Amendment number:	Amendment #1 Substantial
Amendment date:	25 June 2012
Amendment details:	To have a professional company transcribe the one-to-one data from the digital recorder of participants' interviews. The company selected is an independent transcribing company who carry out work for the University of Cambridge.

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Protocol	Version 1	19 August 2011
Notice of Substantial Amendment (non-CTIMPs)	Amendment #1 Substantial	25 June 2012

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Email from CI elaborating on the amendment details, particularly the company who will do the transcribing and what they will do with the recorded material	from CI D A Harris	09 July 2012
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Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

11/EE/0364:	Please quote this number on all correspondence
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Yours sincerely

PP. Har Hari Kaur

**Michael Sheldon (Chair)
Chair**

E-mail: har.hari.kaur@eoe.nhs.uk

Enclosures: List of names and professions of members who took part in the review

*Copy to: Ms Rachel Georgiou, R&D Lead, Research and Development
Department, NHS SalfoR+D, Salford Royal NHS Foundation Trust
Rachel.georgiou@manchester.ac.uk*

*Susan Braid Head of School, University of Salford
s.braid@salford.ac.uk*

APPENDIX B: INFORMATION SHEET AND CONSENT FORM



An exploration of living with motor neurone disease, receiving health care and the impact on self and identity

What is the purpose of the study? My name is Denise Harris. I am a graduate teaching assistant and a full time Master of Philosophy student at the University of Salford. I have worked for the NHS previously and have extensive experience in occupational therapy community services. I am conducting research into people's feelings about motor neurone disease, receiving health care and their changing circumstances. I am interested in people's experiences of their sense of identity.

What will happen if I take part? I will contact you and arrange to visit you in your own home to explain the study further and answer any questions that you may have. I would like to interview you twice throughout the course of the study, in your home or at the neurological centre. Each interview may last between one and two hours and will be recorded on a digital recorder and later transcribed word for word and analysed.

What will happen to the results from this research? The results from this research will be included in my thesis in fulfilment of my Master of Philosophy degree. I will publish the work in professional journals and complete a written report for the University of Salford. Your quotations may be used in publications, but they will be anonymised. Your name will not be mentioned in my thesis, any paper, report or conference.

Are there any risks? Your participation will not impact on your medical treatment(s). If you disclose any painful experiences that you later regret, you will have the opportunity to ask that certain details discussed are later removed.

What are the benefits? The possible benefits for you include the value of reflecting on your experiences with an interested researcher who is also an allied health professional. You may also experience some satisfaction from participating in this study that may help determine the most useful way for allied health professionals to provide care and treatment to meet the needs of motor neurone disease patients.

What are the alternatives? The alternative to participating in this research is not to be interviewed. You are free to withhold any information you prefer not to discuss and you can refuse to answer any questions that I ask. You can participate in the first interview and refuse to talk at later times.

How will my confidentiality be respected? Your medical records will not be looked at for this study. The confidentiality of your interview(s) will be maintained by the researcher and members of the analysis panel, which is a team of researchers. If you mention your name or

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the names of others, they will be replaced by other identifying information. The anonymised transcripts will be stored in a locked cabinet at the University of Salford for 12 months after the duration of my Master of Philosophy study. The recordings will be destroyed as soon as they have been transcribed, as will any identifying information. I would only breach confidentiality if I were concerned for your safety.

Coercion and Withdrawal Statement: I am an independent researcher. Your decision whether or not to participate will not interfere with your future care at this institution. If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without giving an explanation. Your decision to withdraw will not affect your future treatment(s).

Any complaints you have can be made directly to Denise Harris at the address above or alternatively to the Patient Advisory Service (PALS) Tel: 0161 206 2003, pals@srft.nhs.uk; or the Independent Complaints Advocacy Service (ICAS) Tel: 0300 456 8350, manchestericas@carersfederation.co.uk

Denise Harris | Allerton Building | University of Salford | Salford M6 6PU | Tel: 0161 295 4929 | Email: [D.A. Harris@edu.salford.ac.uk](mailto:D.A.Harris@edu.salford.ac.uk)

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Please initial box

I confirm that I have read and understand the information for the above study and have had the opportunity to ask questions.

☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected. I understand that my data will be destroyed if I decide to withdraw.

☐

I understand that the interview will be digitally recorded and that this recording will be listened to by the researcher responsible for this study. I give permission for the researcher to have access to the digital recording.

☐

I agree to take part in the above study, and that any material from the interview can be used in presentations and publications.

☐

I give permission for the researcher to store the anonymised interview transcript for the period of 12 months after the Master of Philosophy study has been completed.

☐

I am unable to provide written consent, but I have indicated via other means of communication that I wish to be a participant in this study. I have selected a witness to sign on my behalf.

☐

Name of Patient

Signature

Date

Researcher

Signature

Date

Witness

Signature

Date

1 copy for patient; 1 for researcher; 1 to be returned to neurological department and kept with hospital notes.

**Denise Harris | Allerton Building | University of Salford | Salford M6 6PU |
Tel: 0161 295 4929 | Email: [D.A. Harris@edu.salford.ac.uk](mailto:D.A.Harris@edu.salford.ac.uk)**

APPENDIX C: PRESENTATIONS

Harris, D., Taylor, J., Ravey, M. (2011) Methodological approach. Salford Post Graduate Research Conference (SPARC) Annual Conference, University of Salford. (Speed presentation).

Harris, D., Taylor, J., Ravey, M. (2012) Methodological approach. MND Annual Conference. NEC Birmingham (Poster presentation).

Harris, D. (2013) Identity and transition symposium. University of Salford (Presented work in progress).

Harris, D., Taylor, J., Ravey, M., and Nightingale, J. (2013) Hermeneutic phenomenology: understanding there is more to a person than motor neurone disease (MND). The Discipline of Occupational Therapy, University of Sydney, Australia (Presented work in progress).

Harris, D., Taylor, J., Ravey, M., and Nightingale, J. (2013) Hermeneutic phenomenology: understanding there is more to a person than motor neurone disease (MND). The Motor Neurone Disease Association 24th International Symposium, Milan, Italy December 2013 (Presenting work in progress).

Published poster

Harris, D., Taylor, J., Ravey, M., and Nightingale, J. (2013) Hermeneutic phenomenology: understanding there is more to a person than MND, Presented at: *International Symposium on Amyotrophic Lateral Sclerosis and Motor Neurone Disease 2013*, 6 - 8 Dec 2013, CW08. Affiliated Society: Motor Neurone Disease Association <http://f1000.com/posters/browse/summary/1094865>

APPENDIX D: TRANSCRIPTION PROTOCOL

STANDARD TEMPLATE

Standard template for transcripts is as follows:

Layout:

University name:
Project name:
File name:
Interviewer:
Date:

Footer: Transcript supplied by: www.academictranscriptions.co.uk

Page number: Centre - bottom of page:

Font: Arial 11pt.

Lines: 1.5

Margins: Justified.

Paragraph: Hanging

Identifiers: I Interviewer
R Respondent

Current typing conventions for all general transcripts:

- All names anonymised in square brackets.
- Unfinished sentence: use ...
- Speech: '.....'
- Hesitations/stuttering: Not included
- Erms, Ers, Mm, Mhm, etc. Only if significant

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- Pauses: Only if significant
- Overlapping text: /...../
- Inaudible/guessed word/words: [counter number?]
- Interruptions by words 'Yeah', 'Right' etc.: [only included if significant]

SLANG:

Please indicate how you would prefer the following words typed in your transcript:

PREFERENCE

Because	'cos
Until	'til
Suppose	'spose
Especially	'specially
Something	somethin'/ summick/ summac
Nothing	nothin'
Isn't it	innit
Going to	gonna
Want to	wanna
I don't know	dunno
I can't	canna
Am not	ain't
you know	y'know
them	'em

Repeated words: ie.

You know
 You know what I mean

INCLUDE

Yes
 Yes

OMIT

APPENDIX E: TRANSCRIPTION

James's transcription

WS55081 File name. Participant 1: Stage 1

I So we could just have a little... if I put that there, and we will have a little chat, and then we'll wind it, and see if we've got it. If that's okay?

R Sure.

I So if I just tell you what the question is: as you know, I'm researching how people experience healthcare from a number of different professionals. So can you please tell me the story of your life, since you first thought there might be something wrong with you? Please begin wherever you like, I will not interrupt you, I will listen to you, and only write down some notes. When you finish I will ask you some questions according to my notes.

R I understand that entirely.

I If I just go back, and rewind.

[trying to rewind]

WS55082

I So it's recording now. We'll keep an eye on that red light.

R Well my condition started in October, 2009, was the first indication I had a brain thing not right. I lost my tennis racket out of my right hand, while I was playing tennis, and I thought hm. And *[clears throat]*, January I went to see the doctor, and I think I am right in suggesting that I ended up having some electro... neuro-electro tests at the [Hospital MRI] as an out-patient, referred by my GP. Then in July of that year, of 2010, I was actually speaking to a colleague, who I met at Wimbledon, who'd had a trapped nerve in his neck, and suggested that maybe I should just have an MRI scan done on my neck, because the surgical procedure to give the nerve more space is quite simple, and it seems to be quite effective. So I thought, hm, armed with that, that's a cracking idea. But by this time I'd already had a referral to the consultant neurologist at the [Hospital MRI]... Well actually it's Dr- from the [Hospital S] clinic, because he has a clinic on a Thursday, I think at the [Hospital MRI]. And I told them I was going to have my neck scanned, and he said, 'Well, in actual fact I would prefer you to have your whole brain and neck scanned', but I didn't get that message until after... because I think I was seeing him on the Thursday, and I was actually having the scan the following Monday. And his request didn't get to me in the post in time. So when I went back to see him in

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September he then suggested that I became an in-patient at [Hospital S] to do more tests, which had a few alarm bells ringing at that point. So on the last day of the Ryder Cup, I remember it well, I found myself being admitted to [Hospital S] Neuro ward for more electro-nerve tests. And then on the following day I think I had a lumbar puncture, and then I had a brain scan, MRI brain scan, and was then diagnosed with MND. Albeit that it was not a clinical definition, because obviously the disease needs to have progressed a bit further for that to be the case. But on the balance of probability that was the case. And by this time my right grip was seriously degenerative from what it had been. And even... You know, you can see the wastage in my hand now, but it was at a stage where it was noticeable when... And erm... So then I became an out-patient at the MND clinic on a quarterly basis from then on. In the meantime, *[clears throat]* I happen to be an insulin dependent Diabetic as well, and a year previous to my first MND issues I'd had a blood test, a whole series of blood tests, run by the Diabetic Centre, in [City M], and not only did they discover that I was Vitamin D deficient, which considering it was January when the tests were done, didn't come as a great surprise to me. They also found that I had a very high [?GADS] antibody count, haematological antibody count for [?GADS], which from my immediate understanding of medical is responsible for a condition known as Stiff Person Syndrome, because it's a response... I think it's the enzyme that allows your muscles to relax. So obviously if you have both sides of the thingy... tension, you can never relax at all. But blatantly that doesn't manifest itself in me. However, [Dr-] suggested that it might be worth attempting a trial with a targeted immunosuppressant [?called Atoximat], which would... anyway, it was a bit of a long shot, but it was worth a try, since the prognosis with MND wasn't great, that this might be a case of my [?GADS] antibody count mimicking MND.

So I duly went into hospital at the rheumatological department... the haematological department, sorry, to have [?Plasmoferesis] done in February of 2011. Actually, I think it was the last week of Jan actually. But it was five separate visits on alternate days having my two and half litres of blood removed, centrifuge, reconstituted with fresh plasma pumped back in, which was quite a tedious procedure, but you know, all went well. *[coughs]*

I Yeah.

R However, we didn't end up getting funding. There was a bit of a funding issue with the costs of the trial. So we didn't actually get the first infusion until the first or second week of September. The [?Plasmoferesis] was designed to remove the [?GADS] antibodies from my blood so that we could start the trial with a clean baseline. And erm... I think the spinal lumbar puncture sample that I'd given in [Hospital H] had also demonstrated a high [?GADS] count, which... It didn't surprise me, but it obviously surprised the medical profession, because there's quite a strong barrier between the blood and the spinal fluid. Blood [?08.31 bain] barrier is quite a difficult one. So the fact they found the antibodies on both sides was, I suppose significant. And I have actually withdrawn from the second infusion, because the reality is that the... nothing I've done in the time since I received my diagnosis, that the rate of degeneration hasn't slowed at all.

I No.

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- R And it didn't seem a lot of point with that reality, going back to have more infusions. And what would have been another two overnight stays in hospital, at some expense, where it seemed like we were flogging a dead horse. So erm... So apart from going back to see both [Dr-], as a patient of this trial, with Professor [Dr-B], who was actually the Head of Rheumatology, he and his team had been responsible for running the [?Rhetoximat] trial. And going to see [Dr name JE] and the rest of his team at [Hospital H] as an out-patient. I've had... Until this year I've had relatively little medical interventions.
- I Okay.
- R I have obviously seen my GP locally, but I've known my GP for twenty odd years, so he understands the situation.
- I Yeah.
- R And in the last four weeks I've now had Social Services coming in to do an assessment of my social care needs.
- I Okay.
- R And I now have a carer that comes in twice a day, but it's not on the medical front, it's just on a... But it's interesting, because obviously as a first time sufferer, with no previous experience of dealing with all of a... it's not... there's not a huge amount of joined up writing, or joining up the dots, or... Yeah, you... I do get the distinct impression that er... Well it's not quite reinventing the wheel, but sometimes it feels like it. You would think anybody that had dealt with MND patients would understand far better than the patient, because they've obviously got more experience in what the requirements might or might not be. Anyway we have had a fantastically intricate [?BioBidet] fitted.
- I Oh, yes. Erm...
- R Because hand dexterity for toileting isn't great. I can still just about feed myself.
- I Okay.
- R But I'm a bit like a bird, pecking the food off my plate with my head, rather than lifting the food to my mouth with my knife and fork.
- I Yeah.
- R And I think my next MND clinical visit is actually May the 9th. So...
- I Yeah. So you go quarterly?
- R Yeah.

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- I Yeah. Yeah.
- R That was... end of Jan, I think was my last visit.
- I Okay. And visit the consultant?
- R Yeah yeah.
- I Yeah. Okay.
- R Inevitably with his teaching students there.
- I Yeah. *[laughs]*
- R Which I don't have a problem with.
- I No. Some might.
- R Well, it's... yeah. They're perfectly within their rights to say 'No', but...
- I Yeah.
- R When I was in [Hospital H] being diagnosed there was an awful lot of people came in to look at me, because I think I have quite physical fasciculation's, which are a diagnostic indicator of things not going well.
- I Yeah. Where were they happening?
- R All over my upper arms, upper body./
- I Really?
- R /Yeah. Yeah. If I'm sitting still, not paying too much attention to other things, I can feel them all the time.
- I Yeah. You don't show any signs of that at the moment. Can you feel them now?
- R Yeah, I can feel them now. Yeah.
- I Yeah. Really?
- R If I had my shirt off you would see them.
- I Yeah yeah. Okay, should we go back to some of the points that you've raised?
- R Sure sure, yeah.

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I I'm just going to stop this for a moment, because we are going to have a little break.

Transcript supplied by
www.academictranscriptions.co.uk

WS55083 File name. Participant 1: Stage 2

R Do you want me to go back, and repeat that?

I Yeah, please.

R I did go to my GP surgery to find out about counselling services, or what was available for my wife, and my children, after my death, and the first foray into that wasn't hugely successful. I think if you weren't a single mum with an alcohol narcotic problem it was quite difficult to put somebody in the right pigeon hole, but eventually I found myself, through the specialist Macmillan nurse, being referred to the Art Therapy Council at the [Hospice EC], who I have been seeing since just before Christmas, on a Monday. And in fact will be going to see again this afternoon. I was delighted that my daughter decided to go and see her, in my place, last week. And I'm trying to persuade my son to do the same, but he, being sixteen, is sort of a bit more of an awkward age. My daughter is nineteen, and she's pretty well grounded in what's going on. Erm... And my wife will go and see her as well, she will...

I Yeah.

R So then that's... that's been excellent. The people at the hospice have been superb. I have a session with the physiotherapist as well. And in fact last week, it was very lucky, I had a little course of reflexology for an hour, which was great.

I It is very nice, isn't it? Yeah.

R I do like people fiddling with my feet.

I Yeah, it is nice. [?It's true].

R Erm... And er... Yeah, I'm continuing to do that. What else am I doing?

I The counsellor... this is from the hospice, you've managed to gain access to their services./

R /Yes yes. I... yeah, absolutely. And that's been useful. It's a funny old situation. You sort of... it's like being in... it's like being on death row without knowing when the executioner is going to pop in. Anyway, we shall be sorting that one out.

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- I Yes. Yeah. Have your family found that service use-... you say your daughter's gone, has she found that service...
- R She thought it was excellent. Really superb.
- I Yeah.
- R And er... It's... I suppose counsellors are a bit like any other human interaction, you obviously... there are certain people you're going to hit it off well with, and there are others who you may not gel with instantly. And I certainly went to see a couple before I found [counsellor] at the hospice, and she's a lovely lady. And more importantly to me, which I thought was probably significant, she's obviously working at the hospice, so she has had quite a number of years in dealing with patients with a terminal illness, which obviously makes my visits to her, as far as I'm concerned, a lot more grounded than they would be with a counsellor that just deals in general counselling of a.../
- I /Definitely... definitely.
- R I mean I went, initially, to say can I find out what's available for the rest of the family, and I've actually found it quite useful myself.
- I Useful. Yeah, which is good. Really good.
- R Not that I've ever had to go to counselling previously, I've always found that chatting to friends or family generally gets round any serious issues. And I suppose that's just part and parcel of my own nature. I'm not sitting there hiding it all under a bushel.
- I No.
- R If somebody wants to talk about it I'll give them plenty.
- I Yeah yeah. I think if we start from the beginning, [P1], you talked about when you was watching Wimbledon, was it?
- R Yeah.
- I And you actually... the first signs, you lost your racket.
- R Well, actually that was in October, '09. I didn't go to Wimbledon until the July, '10.
- I Right.
- R But I'd had two sets of... I think I'd had two sets of neuro-conductivity tests before I went and bumped into this fellow colleague at Wimbledon, who happens to be a fellow cricketer with me at [place B], and he'd had a trapped nerve in his neck.
- I Right.

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- R And we were talking about it, and he said go and get your neck done. But of course it wasn't my neck. Sadly it was a bit more serious.
- I But you're really active with your sports.
- R Oh God, yeah, I used to play tennis three times a week.
- I Yeah.
- R Play cricket, if I could get away with it, I could play three times a week in the summer.
- I Wow.
- R Yeah.
- I So are you still able to engage by watching, or...
- R Er... I... The only thing I'm doing at the moment is I'm watching my son play hockey. I used to play tennis three times a week. Play cricket if I could get away with it, I could play cricket three times a week in the summer. I used to actually referee football matches. I mean I'm a Level 1 football referee. Actually did my training and assessment, oh God, back in 2005. So I used to run around in the winter time, blowing a whistle, in the summer time I'd be playing cricket, or playing tennis. In fact I played tennis all year round. In fact it was on a... we play every Friday evening indoors, and we have been doing for twenty odd years. And as I say, it was losing my racket out of my right hand that indicated to me that something wasn't right. I even went and purchased a left-handed... sorry, a right-hand golf glove, to carry on playing tennis. But after a while I realised that that wasn't going to... And in fact, I think the last game of tennis I played was April, 2010. So/
- I /Did you play golf as well?
- R I did. I started taking up golf after I... Because everybody tells me it's a... as a right-hander it's a left-handed game, with your right hand only along for the ride. And at the time my Motor-Neurone Disease was only affecting me in my right hand, and my right forearm. But progressively it's moved up into my right shoulder, and it's now my left hand is as weak as my right was nine months ago. Because my right side... Although I did manage to carry on refereeing, I did keep up until October of last year, which was quite miraculous really.
- I The next things you said was, becoming an in-patient, where they did more tests. Could you tell me... could you remember a little bit more of about all that happened for you then?
- R Well, I was a bit surprised that I needed to be admitted as an in-patient, because I'd never missed any out-patients' appointments, and I was quite happy to come in and do what was necessary. But Dr- said no, it would be quicker, and more efficient to have

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the tests done as an in-patient than if we try and arrange them as an out-patient. And I think I was in hospital for Monday to Thursday, I think I was discharged on the Thursday. But when I actually think of the tests that I had done, had I been able to have them done concurrently I could probably have done them all in a day, or a day and a half. But obviously it had to fit in with all the test equipment, and the time involved, and the scheduling of the department. So it didn't bother me.

I No.

R I mean I was working for myself, in a set up that wasn't going to create serious grief by being out for five days.

I Yeah.

R But I think for anybody else in a less fortunate position it might have been a bit of an issue.

I Yeah yeah.

R But the staff in the hospital were great.

I Yeah. Was this [Hospital H], or...

R Yeah, it was [Hospital H], yeah.

I [Hospital H]. Yeah.

R [Ward numbers C4 or C5], one or the two.

I Yeah, it is.

R Is it? Yeah.

I That's where I visited, yeah. Yeah, okay. When you first got diagnosed then, how long was that from when you first... with your onset of symptoms, that seems to be.../

R /A year.

I A year.

R Yeah, almost a year to the day in fact.

I Yeah.

R I think I lost my tennis racket out of my hand in October, '09...

I To now [11.04 overlapping dialogue].../

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R /On a Friday.

I Yeah.

R And I was diagnosed/

I In September, was it?

R /first week of October, I think, in 2010.

I Right.

R So it took a year.

I Yeah.

R But you know, it's a difficult one to diagnose at the early stages./

I /It is. It is. And it can quite often get missed as something quite different, as it was doing for you, [?could]...

R The interesting thing is, of course, the [?stork] answer, when people ask how long they've got, is three to five years, and I'm never certain whether that three to five years is from diagnosis, or from actual onset of the disease. So just being silly, if you think the first noticeable symptom occurred in October, '09, I must have had... I must have had the disease prior to that, and... let's say June, and since that time, as I say, the rate of degradation, or degeneration, has been relentless.

I Yeah.

R In spite of my best efforts to...

I Yeah.

R Mentally./

I /Keep positive.

R Yeah yeah.

I Yeah.

R And I suppose as a competitive sportsman you always... you always feel that you have power... positive mental thought you can get... you can get by it. Er... This has beaten me.

I How are your family with the diagnosis? How was it for them hearing about the diagnosis?

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- R Erm... Well, er... In [*clears throat*], in reality, er... life goes on. You know? They can't all put their lives on hold just because I've got a problem. And I'm sure, if you asked them, they would say, 'Well we prefer not to plan it', but you can't sidestep that.
- I No.
- R And erm... They are understandably saddened by it.
- I Yeah.
- R But nobody's... you know, much is the local opinion might be that this is huge cause for people to suffer from depression, we're not... Yeah, we're emotionally resilient enough for that not to be an issue.
- I Yes.
- R And it's very easy for people to confuse sadness with depression, because it seems to be such a modern malaise, and the reality is we aren't depressed, we're just sad./
- I /No. Yeah.
- R Erm...
- I You're getting on with life.
- R Yeah yeah. It's the only way to go.
- I Yeah.
- R And of course that's being amply demonstrated by the fact that the cricket season has started, Grand Prix season has started, football season is boiling up to a fantastic climax, and you just think to yourself, well, hm, am I going to see the end of the football season? Or am I going to see the... Who knows? This is a tricky one.
- I Yeah. Definitely. Out-patients appointments at the clinic, how are those for you? Is that something... you go quarterly, rather than once a month./
- R I do.
- I /Is that choice?
- R No, that's... that's the timing of the clinic's decision.
- I Yeah.
- R They're obviously very keen to ask me about my swallow, and my breathing.
- I Yeah.

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- R And we all know the reason for that. *[clears throat]* I have lost *[sigh]* a stone and a half in weight. And I wasn't a... you know, my BMI index was spot on for my height, so I'm on the low side of it now. Erm... Which is... In fact I don't think I've been ten stone since I was about thirteen, fourteen. *[laughs]* But erm... Yeah. Er... Clinical visits: er yeah, it's becoming a bit more of an issue getting to the clinic. The last few visits I've been able to get... walk to the station, get on the train, and get a bus from [place PG] out to [place SL], but I can't see myself going back in May, to be honest.
- I No.
- R [?Not really, what's the] point.
- I Yeah. You have got the local hospice, could they offer support maybe in place?
- R Well, funnily enough, one of the things that erm [name JE], at my last clinical appointment, put me... gave me a referral to [name TR], I think he's in palliative care at the hospice, and has a clinic at [Hospital MG], but bearing in mind it's April, I haven't heard a dicky bird since.
- I Oh right.
- R We've had a little bit of communications issues with enclosures not getting sent, and people being on leave. But yeah, the time is ticking against me. If they don't get on with it I'll be a name on a list of deceased patients, rather than somebody that is on a palliative care list. But you know, they keep on talking about managing my symptoms. I don't suffer any pain, so I'm not totally certain what symptoms we have that need managing.
- I Right. You talked about swallow, is that getting more difficult for you?
- R Yeah. Yeah it is. I'm not having to modify my eating habits greatly, erm... Jacob's Cream Crackers don't appear on the menu very often now, unfortunately, because of the choke hazard. And I'm obviously a little bit reluctant to find myself eating on my own in the house, just in case I do have a problem. Erm... But that's easily managed by making sure there's somebody here.
- I Yeah.
- R Which is what Social Services are doing. Erm... I can still just about lift a pint to my... Yeah, so... But everything is very close to my body.
- I Yeah.
- R Erm...
- I So Social Services are coming in twice a day to care, is this for help with...

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R Shaving, washing, dressing.

I Right.

R Er... Cooking breakfast, doing my teeth. Erm... It seems a bit daft having the children in the house, but obviously when they're all at school and university, and my wife is at work, and I'm stuck here without any company, so I need help with that. And that's great that they have... they've stepped up to the plate, and they've performed very well.

I Yeah.

R And they're delightful people, so that makes life a lot easier.

I Yeah. Is it the same people coming in most of the time?

R I've had the same lady in for the last two weeks, which is a miracle.

I Good, that helps.

R The assessment people, the enablement people come and do the assessment, and then they tender it out to the local care companies. I hadn't appreciated how it worked, but it works.

I Yeah. I think it's like that everywhere, isn't it? Yeah.

R Yeah. And then I've got a visit from the OT this afternoon, this week we're going to try and examine door opening devices, because key turning is now an issue.

I Yeah.

R It's funny being marooned outside your own front door, because you can't open the... I can't open the door with a key.

I There are obviously pieces of equipment, and they're quite inexpensive to help with that. Erm...

R We haven't got there yet.

I No. Is this the first time then you'll have been involved with the OT? Or is...

R No, I've.../

I /Because you talked about the toilet.

R I've had some involvements with the OT previous to that, sorry, I probably forgot to mention that in the history. Erm... I obviously got a referral from the MND clinic, at [Hospital H], to the local out... Community OT.

I Yeah.

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- R And she's put me in touch with the OT at Social Services. I hadn't appreciated there are OTs dotted around all over the place. I think there are OTs attached to the surgery.
- I Oh really? This is new./
- R /No, maybe not. Maybe it's.../
- I /There could be. There could be, because of the changes with the government.
- R Well they... [name RG] who's based in [place K] is an NHS Community OT, so I see her. And she's referred me to the Social Services OT, who is actually coming to see me this afternoon at three.
- I Is this the lady who... you said you had a bidet fitted, is she...
- R She was... yeah, although funnily enough, the first OT that I saw, who was new to the department, handed it over to another one. So I haven't met the one that's coming in this afternoon.
- I Right.
- R She's picked up the baton from her previous colleague.
- I Ah, yeah yeah.
- R So that's erm...
- I That's really good.
- R Yeah, no, they're doing okay.
- I And you're finding that a useful...
- R Yeah, it's... it... Lucky it wasn't an urgent thing. I said it wasn't urgent, so it's taken... it was only fitted on Wednesday, and... Yeah, I think we engaged in this probably at the end of Feb. So it's taken a few weeks. But we're here, so I haven't had to batter any doors down to get some action.
- I No. Counselling services, I think you talked quite in depth about that, and the advantages for you, haven't you? Obviously because it was a concern for your... about your family, wasn't it? So...
- R Mhm.
- I Because you're into that service now, hopefully that will continue for you all, won't it?
- R I'm sure it will.

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I Yeah.

R I'm sure it will.

I Yeah, okay. We'll take a rest.

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I It was very clear actually, so I'm quite happy with it./

R /Good, excellent.

I So how do you feel your past history impacts on living with Motor-Neurone Disease, and receiving healthcare?

R Oh. How does my past history affect how I live with MND, and receiving treatment. Well, I am not sure I've got an answer to that one, because it's such a... it's such a huge change in your lifestyle, from being an active person, running around, and being a bit of a hopeless case currently. Erm... I... Yeah [*sigh*], I don't know, it's er... I haven't got a definitive answer for that one. I don't think it's... Yeah, this is... If previous history is like walking out of the kitchen, and acquiring MND is like walking through the door into the hall, there's two separate... they're are separate environments, aren't they? And the only common denominator is me. That's probably a question best asked of the other family members. And I suspect the answer to them is... Oh, I don't... no idea. I'm probably not making a lot of sense there. We've faced a... We're just like... Let me have a look at that question again?

I Yeah.

R Well, I suppose the honest answer is for somebody that is very active it's... it's impacted quite a lot really. I am not able to do anything like the things I used to be able to do. As far as receiving healthcare is concerned, I mean I've obviously had a past history of relatively stable health. Not saying necessarily good health, because of my erm... Hyperthyroidism, and insulin dependent Diabetes, but I could live with those. This is a bit more of a tricky one.

As far as receiving healthcare is concerned. Well I suppose it's a bit of shock being in a situation where you're having to be on the receiving end of quite a lot of healthcare. It suddenly makes you wake up to the... either the supreme efficiencies, or deficiencies of the NHS as a healthcare provider. And that er... that definitely has raised a few eyebrows. Erm... Because there's not a huge amount of people in the community that suffer from MND, and as a result there isn't, as far as I can see, a sort of template of care aimed at expressly dealing with MND sufferers. Primarily because of the different way the disease affects different people. But more importantly is the rate of progression that you have for the various different sufferers. So template that's good for Patient A might be crap for Patient B, or Patient C, for that matter. But there isn't... I'm not sure that... who should be the lead agency in that. Maybe the MND Association have a lot more data to deal with, because they are dealing with specific MND sufferers. But since the council care services are the people that are ultimately holding the purse strings, they are presumably currently the lead agents.

I Do you see there being a role for a particular person to monitor without you having to contact services? So they perhaps contact you, and just see how you are, is there anything you need. Kind of like a care.../

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- R /Well... well yeah, but the problem is, you see, you have got Social Services looking after the personal care side of things, which they are doing, and then you've got medical practitioners... You know, when I get to a stage, should I ever get there, that I'm not in a position to self-administer my insulin then the care people can't do that, somebody else has to come in and take care of that, which considering what is involved strikes me as a real sledgehammer to crack a nut. But I can see from a [?leading] responsible body, like the local council, they can't take on medical interventions without the NHS, or the local surgery being involved.
- I That has to be the District Nurses, does it?
- R Yeah. So we could end up with a stupid thing where the District Nurse is coming to see me five times a day when there's a carer in on at least two of the occasions that could do... But you know I am not the one that makes the rules up. If I was the person writing up a care plan for myself it would be structured in an entirely different way to the way that the current mechanism allows.
- I Yeah. Almost like a joint working...
- R Yeah, there's not a lot of joined up writing, I'm afraid to say.
- I No.
- R It's all a bit bitty.
- I Yeah.
- R And erm...
- I Yeah.
- R Yeah, the recent experience I've had with the community OT, at the living centre in [town H], has been... Yeah, the person I was dealing with in January was new to the job, and she didn't last more than eight weeks. And the person that's followed her in is equally new to the job. But there doesn't seem to be any internal case history database for the new people to look up and see what they did for MND patients, because there are, a), very few of them, and b), they are all different, and c), there's not a... Yeah, I'm sure that in their workload it's less than one percent, or less than half a percent, or one in two hundred thousand.
- I Yeah.
- R So...
- I Okay. Thank you for that then. How have health professionals made a difference to your quality of life at this present time?

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- R Oh gosh, mm. I mean [*laughs*], the health professionals that I've seen, and that's, I suppose the counsellor at the hospice, the physiotherapist, the OT, the speech therapist, they've all been diligent and very pleasant to deal with. But in terms of the impact they've had on the quality of my life, the disease has outstripped anything that anybody could have done, in terms of the impact on the quality of my life.
- I Yeah.
- R Is the honest answer to that. I mean, yeah, for all the best intentions, there is nothing they can do to reduce the impact that the disease is having on me. Brutally...
- I Truthfully.
- R Brutally true.
- I Yeah.
- R Yeah.
- I Yeah.
- R Was there anything else to that question?
- I Not really. You've covered that quite well. This question here: How has MND, and receiving healthcare impacted on your self and identity? I think we've kind of... you've covered that, in a way, haven't you?
- R Yeah. I mean I'm... [*sigh*] The disease has obviously radically changed my lifestyle, and receiving healthcare, it just happens to be a consequence of the illness. Yeah. I'm glad I'm receiving the healthcare, I much prefer to be in a situation where I'm receiving it than not receiving it, but I would much prefer not to have the illness in the first place. So on a scale of one to ten the disease has had a sort of impact of nine and a half, and in terms of the healthcare, you know, one or two. Does that makes sense?
- I Yes. Yeah, definitely.
- R Yeah. That's... that's probably the up and down of it. It's not good.
- I No. I think from reading your transcript, and working with your transcript, I found that you... you've been extremely courageous, especially you were carrying on for the first year, and taking up new sports.
- R Well yes, I've taken... the... your reference to the golf, I used to play golf, I just hadn't played for some time.
- I Yeah.
- R Yeah, it was one of those sports that I could carry on doing, because...

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I Yeah.

R At the time, well, it was a six month flash in the pan, but I enjoyed it. And er certainly haven't stopped enjoying it on the telly. Especially we've just had the Masters on, which was great fun. But erm... Yeah. Now, I'm afraid to say, we're down to playing chess, and cards. That's about it. And even then I need a card holder. *[laughs]*

I A lot of the literature talks about people having a loss of self. Do you see that in yourself as you... your self is there and strong, especially in this environment?

R No no. I... I've always had a pretty strong er ego. That's self, isn't it?

I Mhm.

R And er... That's... that is still intact.

I Yeah.

R I don't feel I've had any... I mean I... You could end up, you know, getting very introverted, and I suspect that's what makes... what gets people on the road to being depressed, which is not the case at all. No, I would say that it's had very little impact in how I feel about myself. Mhm, am I deluding myself? I don't know. I'm obviously not the same person, because I am physically challenged. But mentally I'm still there.

I Yeah.

R Yeah.

I Yeah.

R Definitely.

I And do you think that is helped by the fact that you have got such good family support around you? You know, they [?11.59 overlapping dialogue].../

R /Erm... Well yeah, no erm... I think that's probably a challenge that's down to the individual, isn't it? Irrespective of what their family and friends support is, they're the one that are suffering the disease, and therefore it's a challenge that realistically only they can attack. I'm not suggesting that I'm ignoring the assistance I've had from friends and family, but I don't think in terms of one's own assessment of your own identity that that's had a really material impact. Does that make sense?

I Yes. Yeah.

R But then I might be the odd... yeah, the typical square peg in the round hole. Everybody else is, you know, failing through lack of mental fortitude, and I'm just a stubborn old bugger. *[laughs]*

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- I When you say everybody else...
- R Well, I'm talking about other MND sufferers. Because this... it's.../
- I /Oh right, I'm sorry, I thought you meant your family.
- R Well no. I mean, you know, funnily enough it does affect people in different ways.
- I Yeah, of course.
- R Some people, yeah, deny it. 'What's [name J] long-term plans?' was a classic question asked the other day. And of course the answer is, I haven't got any long-term plans. Can't make any long-term plans.
- I No.
- R I mean long-term to me is three to five years hence. Well, we ain't going to be here. Short-term plans, like what am I doing next week, or next month. I suppose the mental robustness part of it is the fact I'm still making plans. If I were, you know... There will come a stage, I'm sure, where we can't make any plans at all.
- I And do you think that positive attitude is keeping maybe the MND a little bit at bay?
- R Well, a very good friend of mine, who is a hypnotherapist and erm... we've had a couple of sessions, and there's no doubt about it, there is... I have a strong belief that what your mind can achieve... conceive, your mind can achieve. But the snag is, as I think I mentioned earlier, in this instance, maybe my positive mental attitude has been beaten by the fact that I can't stop this disease, this degeneration from continuing. And maybe that's not a good basis on building a solid positive mental attitude. It's a bit like building a house on quicksand, it doesn't matter how solid the building is, if you haven't got a decent foundation we're never going to succeed. And I suppose, if I'm honest, I am probably phlegmatically resigned to my fate, rather than fighting it from every corner. But that's... you know, that's with the wisdom of two years hindsight.
- I Did you go for your counselling session?
- R Yesterday? No, I went to [?place RH] instead. But I shall see [counsellor] again next week. So I shall look forward to that. *[clears throat]*
- I Yeah. Good.
- R Anything else?
- I No.
- R That's it?
- I I think we've finished. Yes, thank you very much.

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R You're very very welcome.

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I So, we were talking about...

R Life horizons, weren't we?

I Yeah yeah.

R And the normal state of affairs is, everybody is making plans for the future, because they don't foresee the, or know, unless they've got some death wish, when they are going to die. With this condition, of course, you're not... you've not got the luxury of making long-term plans, because your life horizon is suddenly finite. But it shouldn't make you... Yeah, you can't cast away your lifetime experience of life skills in making decisions about what you are going to do in the future. The only difference is, our future is a bit shorter than you would expect. So it's... Yeah, I suppose you could just throw the whole thing out the window when you have had the diagnosis, and become a complete shivering wreck, or you can stand up to the challenge, and get on with it. And using the skills you've acquired in the rest of your life hold good, don't they? I mean... What else did we miss?

I No, I think.../

R /We've caught it all.

I Yeah, definitely.

R Obviously... I suppose it's out of necessity that you are having to make the plans, rather than, you know, necessarily saying, 'Oh, I'm going to make a plan to do this, that and the other, because I'm looking forward to doing that', in this case I am not really looking forward to doing it, but it still has to be done. Yeah. So, if you go on the MND website, which sometimes the medical practitioners aren't too keen to point you at/

I No.

R /there are one or two people who... who are being obviously used as a test case, whose best advice was, 'Make one plan for yourself, and one plan for the disease'.

I Oh right.

R Yeah.

I Right.

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R So, you know, the person that is getting to the bucket list of things they want to do before they die, you could fill up the whole of the rest of your life doing that, and forget all the tidying up parts, which is what I consider that advice to be aimed at. Making a plan for yourself is enjoy whatever you want to do. Making a plan for the disease is actually keeping your head fixed on the fact that you've got limited time available to do... Yeah. Parkinson's third law, I'm a cracker at that, you know, give me a job to do, and then if I've got all morning to do it in, it will... it will take all morning. If you give me fifteen other things to do, which is why I suppose you should always delegate tasks to busy people, because they have probably better time management skills, than the permanent prevaricators, such as myself... No, I'm only teasing. I am not that bad.

I That's great, thank you very much.

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APPENDIX F: PARTICIPANT STORY

Key to the use of colours:

Heidegger's aspects of temporality applied		
Experiencing MND from first noticing something untoward was happening	Experiencing MND in the present	Projected future living with MND
PAST →	PRESENT →	FUTURE

James's story

Well my condition started in October, 2009, was the first indication I had a brain thing not right. I lost my tennis racket out of my right hand, while I was playing tennis, and I thought hm. And [clears throat], January I went to see the doctor, and I think I am right in suggesting that I ended up having some electro... neuro-electro tests at the [Name of hospital] as an out-patient, referred by my GP. Then in July of that year, of 2010, I was actually speaking to a colleague, who I met at Wimbledon, who happens to be a fellow cricketer with me at [place B], who'd had a trapped nerve in his neck, and suggested that maybe I should just have an MRI scan done on my neck, because the surgical procedure to give the nerve more space is quite simple, and it seems to be quite effective. So I thought, hm, armed with that, that's a cracking idea.

But by this time I'd already had a referral to the consultant neurologist at the [Name of hospital]... Well actually it's Dr- from the [MND] clinic, because he has a clinic on a Thursday, I think at the [Name of hospital]. And I told them I was going to have my neck scanned, and he said, 'Well, in actual fact I would prefer you to have your whole brain and neck scanned', but I didn't get that message until after... because I think I was seeing him on the Thursday, and I was actually having the scan the following Monday. And his request didn't get to me in the post in time. I was diagnosed/ /first week of October, I think, in 2010. So it took a year. But you know, it's a difficult one to diagnose at the early stages/ But of course it wasn't my neck. Sadly it was a bit more serious.

So when I went back to see him in September he then suggested that I became an in-patient at [Name of hospital] to do more tests, which had a few alarm bells ringing at that point. Well, I was a bit surprised that I needed to be admitted as an in-patient, because I'd never missed any out-patients' appointments, and I was quite happy to come in and do what was necessary. But Dr- said no, it would be quicker, and more efficient to have the tests done as an in-patient than if we try and arrange them as an out-patient. So on the last day of the Ryder Cup, I

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remember it well, I found myself being admitted to [Name of hospital] Neuro ward for more electro-nerve tests. And then on the following day I think I had a lumbar puncture, and then I had a brain scan, MRI brain scan, and was then diagnosed with MND. Albeit that it was not a clinical definition, because obviously the disease needs to have progressed a bit further for that to be the case. But on the balance of probability that was the case.

And I think I was in hospital for Monday to Thursday, I think I was discharged on the Thursday. But when I actually think of the tests that I had done, had I been able to have them done concurrently I could probably have done them all in a day, or a day and a half. But obviously it had to fit in with all the test equipment, and the time involved, and the scheduling of the department. So it didn't bother me. I mean I was working for myself, in a set up that wasn't going to create serious grief by being out for five days. But I think for anybody else in a less fortunate position it might have been a bit of an issue, but the staff in the hospital were great.

When I was in [Name of hospital] being diagnosed there was an awful lot of people came in to look at me, because I think I have quite physical fasciculation's, which are a diagnostic indicator of things not going well. All over my upper arms, upper body. / Yeah. Yeah. If I'm sitting still, not paying too much attention to other things, I can feel them all the time. Yeah, I can feel them now. Yeah. If I had my shirt off you would see them.

And by this time my right grip was seriously degenerative from what it had been. And even... You know, you can see the wastage in my hand now, but it was at a stage where it was noticeable when... And erm... So then I became an out-patient at the MND clinic on a quarterly basis from then on. And I think my next MND clinical visit is actually May the 9th, inevitably with his teaching students there, which I don't have a problem with. Well, it's... yeah. They're perfectly within their rights to say 'No', but...

It's such a huge change in your lifestyle, from being an active person, running around, and being a bit of a hopeless case currently. If previous history is like walking out of the kitchen, and acquiring MND is like walking through the door into the hall, there's two separate... they're are separate environments, aren't they? And the only common denominator is me. Well, I suppose the honest answer is for somebody that is very active it's... it's impacted quite a lot really. I am not able to do anything like the things I used to be able to do. As far as receiving health care is concerned, I mean I've obviously had a past history of relatively stable health. Not saying necessarily good health, because of my erm... Hyperthyroidism, and insulin dependent Diabetes, but I could live with those. This is a bit more of a tricky one.

I used to play tennis three times a week. Play cricket if I could get away with it, I could play cricket three times a week in the summer. The only thing I'm doing at the moment is I'm watching my son play football. I used to actually referee football matches. I mean I'm a Level 1 football referee. Actually did my training

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and assessment, oh God, back in 2005. So I used to run around in the winter time, blowing a whistle, in the summer time I'd be playing cricket, or playing tennis. In fact I played tennis all year round. In fact it was on a... we play every Friday evening indoors, and we have been doing for twenty odd years. And as I say, it was losing my racket out of my right hand that indicated to me that something wasn't right. I even went and purchased a left-handed... sorry, a right-hand golf glove, to carry on playing tennis. But after a while I realised that that wasn't going to... And in fact, I think the last game of tennis I played was April, 2010. So I used to play golf; I just hadn't played for some time. Yeah, it was one of those sports that I could carry on doing, because... At the time, well, it was a six month flash in the pan, but I enjoyed it. And er certainly haven't stopped enjoying it on the telly. Especially we've just had the Masters on, which was great fun. But erm... Yeah. Now, I'm afraid to say, we're down to playing chess, and cards. That's about it. And even then I need a card holder. [Laughs]

So.../ In spite of my best efforts to... Mentally. / And I suppose as a competitive sportsman you always... you always feel that you have power... positive mental thought you can get... you can get by it. Er... This has beaten me.

But you know they keep on talking about managing my symptoms. I don't suffer any pain, so I'm not totally certain what symptoms we have that need managing. I do not have to modify my eating habits greatly, erm... Jacob's Cream Crackers don't appear on the menu very often now, unfortunately, because of the choke hazard. And I'm obviously a little bit reluctant to find myself eating on my own in the house, just in case I do have a problem. Erm... But that's easily managed by making sure there's somebody here, which is what Social Services are doing. Erm... I can still just about lift a pint to my... Yeah, so... But everything is very close to my body.

They're obviously very keen to ask me about my swallow, and my breathing. And we all know the reason for that. [Clears throat] I have lost [sigh] a stone and a half in weight. And I wasn't a... you know, my BMI index was spot on for my height, so I'm on the low side of it now. Erm... Which is... In fact I don't think I've been ten stone since I was about thirteen, fourteen. [Laughs] But erm... Yeah. Er... Clinical visits: er yeah, it's becoming a bit more of an issue getting to the clinic. The last few visits I've been able to get... walk to the station, get on the train, and get a bus from [place PG] out to [MND clinic], but I can't see myself going back in May, to be honest. No not really, what's the point.

I have obviously seen my GP locally, but I've known my GP for twenty odd years, so he understands the situation. And in the last four weeks I've now had Social Services coming in to do an assessment of my social care needs. And I now have a carer that comes in twice a day, but it's not on the medical front, it's just on a... But it's interesting, because obviously as a first time sufferer, with no previous experience of dealing with all of a... it's not... there's not a huge amount of joined up writing, or joining up the dots, or... Yeah, you... I do get the distinct impression that er... Well it's not quite reinventing the wheel, but sometimes it feels like it. You would think anybody that had dealt with MND patients would understand far

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better than the patient, because they've obviously got more experience in what the requirements might or might not be. Anyway we have had a fantastically intricate [Bio-Bidet] fitted, because hand dexterity for toileting isn't great. I can still just about feed myself. But I'm a bit like a bird, pecking the food off my plate with my head, rather than lifting the food to my mouth with my knife and fork.

Erm... Because there's not a huge amount of people in the community that suffer from MND, and as a result there isn't, as far as I can see, a sort of template of care aimed at expressly dealing with MND sufferers. Primarily because of the different way the disease affects different people. But more importantly is the rate of progression that you have for the various different sufferers. So template that's good for Patient A might be crap for Patient B, or Patient C, for that matter. But there isn't... I'm not sure that... who should be the lead agency in that. Maybe the MND Association has a lot more data to deal with, because they are dealing with specific MND sufferers. But since the council care services are the people that are ultimately holding the purse strings, they are presumably currently the lead agents.

The assessment people, the enablement people come and do the assessment, and then they tender it out to the local care companies. I hadn't appreciated how it worked, but it works. Yeah. Social services come in twice a day to help with shaving, washing, dressing, cooking breakfast, doing my teeth. Erm... It seems a bit daft having the children in the house, but obviously when they're all at school and university, and my wife is at work, and I'm stuck here without any company, so I need help with that. And that's great that they have... they've stepped up to the plate, and they've performed very well. And they're delightful people, so that makes life a lot easier. I've had the same lady in for the last two weeks, which is a miracle.

And then I've got a visit from the OT this afternoon, this week we're going to try and examine door opening devices, because key turning is now an issue. Its funny Being marooned outside your own front door, because you can't open the... I can't open the door with a key. I've had some involvements with the OT previous to that, sorry, I probably forgot to mention that in the history. Erm... I obviously got a referral from the MND clinic, at [Name of hospital], to the local community OT. And she's put me in touch with the OT at Social Services. I hadn't appreciated there are OTs dotted around all over the place. I think there is OTs attached to the surgery. The first OT that I saw, who was new to the department, handed it over to another one. So I haven't met the one that's coming in this afternoon. She's picked up the baton from her previous colleague. But there doesn't seem to be any internal case history database for the new people to look up and see what they did for MND patients, because there are, a), very few of them, and b), they are all different, and c), there's not a... Yeah, I'm sure that in their workload it's less than one percent, or less than half a percent, or one in two hundred thousand.

The problem is, you see, you have got Social Services looking after the personal care side of things, which they are doing, and then you've got medical practitioner... You know, when I get to a stage, should I ever get there, that I'm not in a position to self-administer my insulin then the care people can't do that,

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somebody else has to come in and take care of that, which considering what is involved strikes me as a real sledgehammer to crack a nut. But I can see from a leading responsible body, like the local council, they can't take on medical interventions without the NHS, or the local surgery being involved. So we could end up with a stupid thing where the District Nurse is coming to see me five times a day when there's a carer in on at least two of the occasions that could do... But you know I am not the one that makes the rules up. If I was the person writing up a care plan for myself it would be structured in an entirely different way to the way that the current mechanism allows.

As far as receiving health care is concerned. Well I suppose it's a bit of shock. Being in a situation where you've have to be on the receiving end of quite a lot of health care. It suddenly makes you wake up to the... either the supreme efficiencies, or deficiencies of the NHS as a health care provider. And that er... that definitely has raised a few eyebrows.

Oh gosh, mm. I mean [laughs], the health professionals that I've seen, and that's, I suppose the counsellor at the hospice, the physiotherapist, the OT, the speech therapist, they've all been diligent and very pleasant to deal with. But in terms of the impact they've had on the quality of my life, the disease has outstripped anything that anybody could have done, in terms of the impact on the quality of my life. Yeah. I mean I'm... [Sigh] The disease has obviously radically changed my lifestyle, and receiving health care, it just happens to be a consequence of the illness. Yeah. I'm glad I'm receiving the health care, I much prefer to be in a situation where I'm receiving it than not receiving it, but I would much prefer not to have the illness in the first place. So, on a scale of one to ten, the disease has had a sort of impact of nine and a half, and in terms of the health care, you know, one or two. Does that make sense? Yeah. That's... that's probably the up and down of it. It's not good.

Well, a very good friend of mine, who is a hypnotherapist and erm... we've had a couple of sessions, and there's no doubt about it, there is... I have a strong belief that what your mind can conceive, your mind can achieve. But the snag is, as I think I mentioned earlier, in this instance, maybe my positive mental attitude has been beaten by the fact that I can't stop this disease, this degeneration from continuing. And maybe that's not a good basis on building a solid positive mental attitude. It's a bit like building a house on quicksand, it doesn't matter how solid the building is, and if you haven't got a decent foundation we're never going to succeed. And I suppose, if I'm honest, I am probably phlegmatically resigned to my fate, rather than fighting it from every corner. But that's... you know, that's with the wisdom of two years hindsight.

I mean I... You could end up, you know, getting very introverted, and I suspect that's what makes... what gets people on the road to being depressed, which is not the case at all. No, I would say that it's had very little impact in how I feel about myself. Mhm, am I deluding myself? I don't know. I'm obviously not the same person, because I am physically challenged. But mentally I'm still there. I think that's probably a challenge that's down to the individual, isn't it? Irrespective of

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what their family and friends support is, they're the one that are suffering the disease, and therefore it's a challenge that realistically only they can attack. I'm not suggesting that I'm ignoring the assistance I've had from friends and family, but I don't think in terms of one's own assessment of your own identity that that's had a really material impact. Does that make sense? But then I might be the odd... yeah, the typical square peg in the round hole. Everybody else is, you know, failing through lack of mental fortitude, and I'm just a stubborn old bugger.
[Laughs]

My family can't all put their lives on hold just because I've got a problem. And I'm sure, if you asked them, they would say, 'Well we prefer not to plan it', but you can't sidestep that. And erm... They are understandably saddened by it. But nobody's... you know, much is the local opinion might be that this is huge cause for people to suffer from depression, we're not... Yeah, we're emotionally resilient enough for that not to be an issue. And it's very easy for people to confuse sadness with depression, because it seems to be such a modern malaise, and the reality is we aren't depressed, we're just sad. / Erm... I am getting on with life it's the only way to go. And of course that's being amply demonstrated by the fact that the football season has started, Grand Prix season has started, football season is boiling up to a fantastic climax, and you just think to yourself, well, hm, am I going to see the end of the football season? Or am I going to see the... Who knows? This is a tricky one.

Well, funnily enough, one of the things that erm [Name of consultant], at my last clinical appointment, put me... gave me a referral to [Name of hospice consultant], I think he's in palliative care at the hospice, and has a clinic at [Name of hospital], but bearing in mind it's April, I haven't heard a dicky bird since. We've had a little bit of communications issues with enclosures not getting sent, and people being on leave. But yeah, the time is ticking against me. If they don't get on with it I'll be a name on a list of deceased patients, rather than somebody that is on a palliative care list.

The interesting thing is, of course, the stock answer, when people ask how long they've got, is three to five years, and I'm never certain whether that three to five years is from diagnosis, or from actual onset of the disease. So just being silly, if you think the first noticeable symptom occurred in October, '09, I must have had... I must have had the disease prior to that, and... Let's say June, and since that time, as I say, the rate of degradation, or degeneration, has been relentless.

I did go to my GP surgery to find out about counselling services, or what was available for my wife, and my children, after my death, and the first foray into that wasn't hugely successful. I think if you weren't a single mum with an alcohol narcotic problem it was quite difficult to put somebody in the right pigeon hole, but eventually I found myself, through the specialist Macmillan nurse, Being referred to the Art Therapy Council at the [Name of Hospice], who I have been seeing since just before Christmas, on a Monday. And in fact will be going to see again this afternoon. I was delighted that my daughter decided to go and see her, in my place, last week. And I'm trying to persuade my son to do the same, but he,

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being sixteen, is sort of a bit more of an awkward age. My daughter is nineteen, and she's pretty well grounded in what's going on. Erm... And my wife will go and see her as well, she will... So then that's... that's been excellent. The people at the hospice have been superb. I have a session with the physiotherapist as well. And in fact last week, it was very lucky; I had a little course of reflexology for an hour, which was great. I do like people fiddling with my feet. Erm... And er... Yeah, I'm continuing to do that. What else am I doing?

My daughter thought it was excellent. Really superb. And er... It's... I suppose counsellors are a bit like any other human interaction, you obviously... there are certain people you're going to hit it off well with, and there are others who you may not gel with instantly. And I certainly went to see a couple before I found [Name of counsellor] at the hospice, and she's a lovely lady. And more importantly to me, which I thought was probably significant, she's obviously working at the hospice, so she has had quite a number of years in dealing with patients with a terminal illness, which obviously makes my visits to her, as far as I'm concerned, a lot more grounded than they would be with a counsellor that just deals in general counselling of a.../

I mean I went, initially, to say can I find out what's available for the rest of the family, and I've actually found it quite useful myself. Not that I've ever had to go to counselling previously, I've always found that chatting to friends or family generally gets round any serious issues. And I suppose that's just part and parcel of my own nature. I'm not sitting there hiding it all under a bushel. If somebody wants to talk about it I'll give them plenty. And that's been useful. It's a funny old situation. You sort of... it's like being in... It's like being on death row without knowing when the executioner is going to pop in. Anyway, we shall be sorting that one out.

Well, I'm talking about other MND sufferers. Because this... it's.../ Well no. I mean, you know, funnily enough it does affect people in different ways. Some people, yeah, deny it. 'What's [name J] long-term plans?' was a classic question asked the other day. And of course the answer is, I haven't got any long-term plans, I can't make any long-term plans. I mean long-term to me is three to five years hence. Well, we ain't going to be here. Short-term plans, like what am I doing next week, or next month. I suppose the mental robustness part of it is the fact I'm still making plans. If I were, you know... There will come a stage, I'm sure, where we can't make any plans at all.

We were talking about life horizons, weren't we? And the normal state of affairs is, everybody is making plans for the future, because they don't foresee the, or know, unless they've got some death wish, when they are going to die. With this condition, of course, you're not... you've not got the luxury of making long-term plans, because your life horizon is suddenly finite. But it shouldn't make you... Yeah, you can't cast away your lifetime experience of life skills in making decisions about what you are going to do in the future. The only difference is our future is a bit shorter than you would expect. So it's... Yeah, I suppose you could

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just throw the whole thing out the window when you have had the diagnosis, and become a complete shivering wreck, or you can stand up to the challenge, and get on with it. And using the skills you've acquired in the rest of your life hold good, don't they? I mean... What else did we miss?

/We've caught it all. Obviously... I suppose it's out of necessity that you are having to make the plans, rather than, you know, necessarily saying, 'Oh, I'm going to make a plan to do this, that and the other, because I'm looking forward to doing that', in this case I am not really looking forward to doing it, but it still has to be done. Yeah. So, if you go on the MND website, which sometimes the medical practitioners aren't too keen to point you at/ /there are one or two people who... who are Being obviously used as a test case, whose best advice was, 'Make one plan for yourself, and one plan for the disease'.

So, you know, the person that is getting to the bucket list of things they want to do before they die, you could fill up the whole of the rest of your life doing that, and forget all the tidying up parts, which is what I consider that advice to be aimed at. Making a plan for yourself is to enjoy whatever you want to do. Making a plan for the disease is actually keeping your head fixed on the fact that you've got limited time available to do... Yeah. Parkinson's third law, I'm a cracker at that, you know give me a job to do, and then if I've got all morning to do it in, it will... it will take all morning. If you give me fifteen other things to do, which is why I suppose you should always delegate tasks to busy people, because they have probably better time management skills, than the permanent prevaricators, such as myself... No, I'm only teasing. I am not that bad.

APPENDIX G: PRACTICE GUIDELINES

Services required along the Year of Care pathway			
Milestone		Following diagnosis	MND Association Care Centres and RCDA
Generic needs at and post diagnosis	Neurological assessment and diagnosis in out-patient clinic or as inpatient. Refer to allied health professionals according to presenting symptoms and need, and to MND or neurology specialist nurse/service or regional MND Care Centre. Refer to the MND Association.	Riluzole prescription; early discussion about prognosis and role of palliative care services available, particularly for social and psychological support. Link in with local MND multidisciplinary team if available. Identify key worker and refer to Social Services adult disability team. Identify other key professionals and ensure everyone knows who is involved, particularly when there is no dedicated MDT. Referral to welfare and benefits advisers, and, if appropriate, to Independent Living Fund. Give general advice on healthy living, balancing activities to maintain independence. Consider need for psychological support for family. Consider ability to drive and inform DVLA. Ensure ongoing communication between all members of team and family including reviews.	The MND Association Care Centres provide opportunities to join clinical trials, participate in the DNA Bank and tissue donation. Practical, emotional, social and financial support is available via the Association throughout the progression of the disease. This includes MND Connect (advice and information service), Equipment Loan, Financial Support, Association Visitors and Branches/Groups. The RCDA works with statutory, voluntary and independent sector providers to promote and influence provision of timely and equitable access to a co-ordinated network of care.
Loss of function	Service or actions required to delay, ameliorate and support prior to loss of function	Services required once loss of function occurs.	Other actions, including information and support required by patient, carer and family.

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Loss of use of arms	Occupational therapy to assess and recommend equipment and strategies to aid and promote independence. Refer to Adult Social Care for Carers' Assessment.	Refer to occupational therapy for equipment to maintain independence with ADL. Referral to specialist centre for assessment, management and equipment. Refer to Social Services for care package.	Referral to specialist centre e.g.: Oxford Centre for Enablement for assessment, management and equipment.
Loss of ability to walk	Physiotherapy for general exercise programme and to aid independence. Occupational therapy review of mobility within the home environment and introduction of safety equipment such as stair rails, stair lift.	Ongoing Therapist input to review safety of mobility and transfers and discuss orthotics/aids; referral to wheelchair services. Ongoing review to monitor pressure area care. Review of home set-up and provision of adaptations as appropriate such as stair lifts, through-floor-lifts, and consideration of living downstairs, bathroom adaptations. Consider costs of adaptations and involve welfare and benefits advisers. Involve housing departments if re-housing required. Consider palliative care involvement (day hospice to address social losses of immobility).	Consider transport services such as Taxicard Schemes, hospital transport, Dial-a-ride. Provide information on adapted vehicle loan schemes/funding assistance for vehicle purchase. Provide information on Disabled Facilities Grants.
Loss of ability to manage personal hygiene and care	Occupational therapy referral to assess aids needed such as commode, closomat, bathroom adaptations; aids for dressing/undressing, clothing advice. Physiotherapy/occupational therapy to review toilet/bath transfers safety.	Physiotherapy/occupational therapy input for manual handling advice for transfers, introduction of hoist, consider appropriate sling for toileting; social work referral to address care package needs and provide carers assessment. Care package set-up according to need and consider referral for continuing care assessment. Refer to district nursing service for continence advice, provision of equipment; review of constipation and immobility, pressure area management. Refer to chiropody services.	Information re support for family/carers, e.g. Crossroads Caring for Carers, respite care, palliative care input . Consider psychological impact of loss of function/dignity/role. Consider other options such as nursing home placement if care at home not feasible.

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Loss of speech	SaLT to provide advice and exercises, teaching of communication methods and introduction of some basic equipment such as voice amplifier. Discuss advanced care planning, ⁶ and ADRT whilst still able to communicate.	Introduction of further communication aids and ongoing review and adaptation. Referral to specialist electronic assistive technology team. Referral for specialist palliative care support.	Ongoing monitoring and review to facilitate adaptation of equipment as needs change. Ongoing communication between all members of team and family for both practical support, e.g.: consider Medlink, alarm (BT); call alert message system; and advanced care planning.
Loss of ability to swallow	SaLT to provide swallowing advice, including eating positioning, saliva control, diet modification, oral exercise and mouth care. Dietician to monitor weight, advise on supplements and provide general nutritional advice.	Refer to Gastroenterologist/Radiologist for consideration of PEG/RIG, with review by Respiratory Physician and Physiotherapist to determine suitability of procedure. Supervision of PEG/RIG with ongoing input from SaLT and dietetics, ongoing monitoring saliva control and teaching of carers and family to use suction machine. Involvement of acute hospital, community and palliative care teams.	Ensure monitoring of respiratory status/function by neurologist, respiratory physician, physiotherapist and SaLT to determine suitability and feasibility of procedure for PEG insertion; discuss quality of life issues.
Loss of respiratory function	Refer to Respiratory Physician. Physiotherapist to monitor status, encourage breathing exercises, look for early signs and symptoms, teach assisted cough technique. SaLT to emphasise effective feeding positioning and techniques to avoid choking and	Respiratory Physician assessment with home oxygen saturation monitoring if available. Check respiratory function at clinic appointments to monitor lung capacity, with overnight hospital stay for sleep study assessment. Provision of NIPPV if appropriate, hospital stay for set-up and	Consider use of medication, held at home, to ameliorate the symptoms, e.g.: MND Association <i>Breathing Space Kit</i> .

⁶ Advanced care planning (ACP) - is a voluntary process of discussion about future care between an individual and their care providers, irrespective of discipline.

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	aspiration. Provide suction machine and cough assist machine for clearing secretions.	education of pwMND and family; on-call community support at home with NIPPV; Community Respiratory Nurse input. Provision of nebuliser and humidifier. Care package to support NIPPV. Need for district nursing input. Palliative care input , including respite care, for episodes of breathlessness. Discussion of ADRT. Management of requests for tracheostomies.	
Loss of cognitive function	Support for pwMND and the family/carers. Counselling support and education. Continuing care assessment for psychiatric needs. Consider need for Power of Attorney, advanced care planning and ADRT.	Possible neuropsychological assessment to determine mental capacity, particularly as care needs and mental health needs increase. Referral to community mental health team for social work or community psychiatric support and access to specialist services.	Respite and carer support via palliative care team, dementia support groups and carer organisations, such as Crossroads Caring for Carers.
Prior to death	Palliative care team , District Nurse and GP to ascertain preferred place of care and support the end of life (if not already discussed). Night sitters towards last days if at home. Ensure that all services, including out of hours services and ambulance service have knowledge of pwMND and their needs and wishes.		Bereavement support via relevant local services, e.g.: specialist palliative care/Hospice Team, independent local bereavement services.

APPENDIX H: PSYCHO-EXISTENTIAL SUFFERING

(Taken from Murata and Morita, 2006)

Relationships	People achieve a sense of meaning from relationships.	It is viewed as psycho-existential suffering for a patient to lose relationships that have provided their Being and meaning.	Relationships	Comfort or discomfort related to relationships with others, such as wishing to be with family, knowing family is prepared, resolving interpersonal conflicts, and interpersonal guilt.
			Burden to others	Sense that one is a burden to family, medical professionals, and society.
Autonomy	People achieve a sense of meaning from independence, control over the future, a role, or self-continuity.	It is viewed as psycho-existential suffering when a patient loses their autonomy.	Control	Sense/wishes, priorities of control over physical functioning - independence, cognitive functioning -mental alertness, and the future - control of what happens in the future; medical conditions or personal affairs.
			Continuity of self	Sense/wishes, priorities that the core of the self-role, enjoyable activity, beauty, pride, individualized value system continue to be constant.

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Temporality	People create the future by accepting the existence of a past that has already occurred, opening possibilities in the future in the reality into which they have been cast, and find meaning in the present by trying to realize the envisioned future (Kawa, et al., 2003).	It is viewed as psycho-existential suffering when a patient loses their future.	Generativity	Sense/wishes, priorities that what is important for oneself will be taken over, remembered, or last even after death.
			Death anxiety	Struggle with death-evoked anxiety in one's way, such as accepting, denying, fighting, or letting go.
			Hope	Sense/wishes, priorities of maintaining hope on a variety of levels, such as recovery, better quality of life, fulfilment of specific goals, meaning, or unspecific general expectations that something good may happen in the future.

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Word Count 65,998

Appendices	17,055
Chapters	48,943